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What the future holds: Older people caring for adult sons and daughters with disabilities

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Report for the Changing Ageing Partnership (Cap)
Institute of Governance, School of Law, Queen's University Belfast.

older louder stronger

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What the future holds:

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This report is dedicated to all carers

who devote their lives to individuals with disabilities.

“The opposite of wishful thinking is intellectual honesty.” (Skinner, 1953*)*

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List of contents

What the future holds:

Older people caring for adult sons and daughters with disabilities

Executive Summary

Improvements in healthcare have lead to unprecedented population ageing that affects all cultures, gender, and levels of impairment (Magrill, 2005). This has profound implications, especially for ageing parents who continue to be the main carer for adult sons and daughters with disabilities. While *Valuing People* (Department of Health, 2001) and *Valuing Carers* (DHSSPS, 2002) demand that service providers must have plans for all individuals with learning disabilities who live with older carers and ensure service user choice and control, health and social care systems have not kept apace (Bamford, 2006; McDowell & Mawhinney, 2007).

This report is based on interviews with 29 parents reporting on 27 adult sons and daughters with disabilities in which issues were explored in relation to present life circumstances, support from family and service providers, levels of health and impairment, and futures planning. Findings expose high levels of commitment and love for sons and daughters in the face of, oftentimes, severe disabilities and carers' ill health.

Carers experienced twice the level of psychological stress than the general population and had to make life adjustments that do not concur with expectations of peers who have typically developed adult sons and daughters. They faced worry and loneliness, they experienced severe lack of statutory

support, and they reported near non-existence of futures planning, especially in cases with highest levels of impairment. A complex pattern of social and psychological interdependence became apparent. Implications of this research confirm a ticking 'time bomb' (Caulkin, 2008) of service needs that have to be considered carefully by policy makers, service providers, and professionals.

- **Main findings**

1. 38% of the carers were over pensionable age (range 47-84 years); average age of sons and daughters with disabilities was 33.48 years.
2. Caring was a full-time job for 90% of the participants and included physical care in 86% of the cases.
3. Concern about psychological health of carers was twice that of the general population (35% vs 17%).
4. Participants (79%) enjoyed spending time and going out with their sons and daughters with disabilities.
5. Greatest challenges for participants (86%) were lack of respite, dealing with difficult behaviours, including physical aggression, and meeting sons/daughters' social needs.
6. 69% of the participants received support from their family, while 31% did not have any family support.
7. Only 14% of participants received help from friends or neighbours.
8. 79% of the participants did not have a care plan for their son/daughter with disabilities, although care arrangements had changed over the years in 69% of the cases.

9. 66% of the participants had discussed necessary changes with social services and 36% did not receive help or had to fight for help.
10. Most of the participants (76%) stated that their own health was good or fair, despite suffering from various health problems.
11. Two-thirds of the participants (67%) relied on informal family arrangements in case the main carer fell ill; in 48% of cases there were no adequate substitute care arrangements.
12. Most of the participants (72%) had not considered making long-term plans for the future care of their sons or daughters with disabilities.

- **Recommendations**
- Evidence-based early interventions need to be in place to enhance life skills and choices of individuals with disabilities.
- An advocate should be available to each family throughout the life span, to help set up and coordinate appropriate networks of support well in advance.
- Suitable alternative accommodation needs to be available for adults with all levels of additional individual needs.
- Support services for adults with disabilities who live at home and their carers should be easily accessible, especially in rural areas.
- Education and training for service providers needs to focus on evidence-based best practice to meet the needs of these families.

What the future holds:

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Introduction

The research question on which this report is based came from discussions with parents of children with disabilities who were worried about the lack of adequate services and supports and the failure of government and service agencies to provide adequate planning for the future (Keenan, Dillenburger, Byrne, & Doherty, 2007). These parents expressed the need to increase their knowledge and awareness regarding the issues to be faced by them in the future, especially as they and their children grow older.

Parenthood is a lifelong process and issues of service provision and futures planning permeate throughout the process of bringing up a child with disabilities. Appropriate interventions and treatments provided routinely by statutory bodies at an early age can go a long way in alleviating worry about the future, because they enhance skills levels and thus increase future options and choices for these families (Department of Health, 2007). Ultimately, however, most parents tend to shoulder the responsibility for making decisions regarding their offspring on their own. This report bears witness to the issues, stresses, and worries of older parents of adult sons and daughters with disabilities and should be taken seriously by policy makers, service providers, and other governmental bodies charged with caring for individuals with disabilities and their carers.

One of the key messages from this report is that adequate services are necessary earlier in the lives of families with disabilities, focussing especially on independent living skills. Other key messages are that appropriate services, such as sheltered accommodation, must be available so that parents can trust that their offspring with disabilities are adequately catered for throughout adulthood. These service choices must be available during early adulthood, not merely after parents become incapacitated. Of course, parents and adults with disabilities should receive guidance and help with future planning but this would be easier to accomplish if there was a wide variety of appropriate options that are perceived as safe, desirable, and offering highest quality of support and care.

Section 1: Carers and 'dependents': A dynamic relationship

- **Ageing carers**

The number of children diagnosed with disabilities is increasing and together with an increase in parental age at birth this means that more people are carers well into their old age (Minnes & Woodford, 2005). For 82% of adults with disabilities the main support comes from an informal carer who usually lives in the same household (ABS, 1999; Argyle, 2001).

"Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability" (Carers Northern Ireland, 2002, p.6). The definition of learning disability includes a "significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development" (Department of Health, 2001, paras 1.4 – 1.7.). The definition of physical impairments includes a range of orthopaedic, neuromuscular, cardiovascular and pulmonary disorders that may or may not necessitate the use of assistive devices, including wheelchairs.

There are many worries and challenges for older parents of adult dependant sons and daughters, but one of the most stressful is this question: 'What will happen when we become unable to care for our child ourselves?' (Freedman, Krauss, & Seltzer, 1997; Stokes, 1977). Intra-family solutions include siblings

or other relatives who act as carers, however, while siblings may be willing to become carers in the future, parents oftentimes are reluctant to burden them with care-giving responsibilities (Griffith & Unger**,** 1994). Sheltered housing is another possibility, however, frequently there is little provision, lack of information about options, lack of practical support, and a sense of marginalisation for older parents (Gilbert, Lankshear, & Petersen, 2007). It is thought that ultimately parents may require professional help with planning for the future (Sherman, 1997; Smith, Hatfield, & Miller, 2000; Smith & Tobin, 1989).

This situation has implications for service provision and policy planning, not only for families but also for policy makers, politicians, professionals, researchers, and ultimately, every taxpayer. Future governance of services for this growing population must include resource allocation, decision making, and community planning (Johnston & Martin, 2005). Buckner and Yeandle (2007) estimated that unpaid carers save in excess of £87 billion for the UK economy, a sum that exceeds the total expenditure on the NHS.

- **Prevalence**

In England and Wales statistics of older people providing unpaid care make for grim reading (Census, 2001). There are 5.2 million unpaid carers, of whom over one million provide more than 50 hours of care per week. Over half of the unpaid carers are over 55 years of age and nearly a quarter of them are not in good health themselves. There are over 336,000 people aged 90+ years, 4,000 of who provide 50 or more hours of unpaid care per week. Men are

over-represented in this age group, providing nearly half of the unpaid care hours, although they represent only just over a quarter of the population in this age bracket (Dahlberg, Demack, & Bambra, 2007).

In the general population aged 50-59 years, more than 24.6% of women and 17.9 % of men provide some unpaid care. Many of the unpaid carers are also in paid employment. Of the 15.2 million full-time employees (aged 16-74) in England and Wales, 1.6 million provide some unpaid care and 144,000 providing 50 or more hours a week (Fisher, 1994). In addition, 273,000 of the 2 million people (aged 16-74) who are permanently sick or disabled provide some unpaid care, and 105,000 of them provide 50 or more hours care.

In sum, unpaid and informal care giving is most common in groups that are vulnerable themselves, i.e., older people who may be frail themselves, middle-aged women who already have to balance family and work, and people who experience poor health themselves.

In Northern Ireland, Census (2001) indicates that there are approximately 185,000 unpaid carers, 25% of whom are providing more than 50 hours of care per week, and almost 39,000 of whom who are aged 60+ (DHSSPS 2006). Although precise figures for older parents caring for sons and daughters with disabilities are not available, MENCAP (2002) indicates that in England 20% of all adults with learning disabilities (n=29,000) are living with a parent aged 70+. This estimate is confirmed in Northern Ireland by the *Informal Carers Report* (DHSSPS, 2001) which found that 15% of the

respondents were aged 65 or over and an estimated 85% of the dependants had a disability, e.g., 16% had a sight or hearing difficulty, 6% had a learning disability, and 11% had mental health needs. With regard to the relationship with the dependent, 30% of the unpaid carers were caring for a child (age of 'child' not published). The report identified the contribution by unpaid carers and their role in providing a secure and familiar environment for people with disabilities and stated that they were "the backbone of community care" (DHSSPS, 2001).

- **Socio-demographics**

Recent trends in population ageing are unprecedented, enduring, and pervasive across cultures, gender and disability and have profound implications for everyone's life. In addition, people wait longer before starting a family and parental age at birth has been linked to risk for the child. For example, a detailed study of the entire cohort of 132,844 children born between 1995-1999 at the Kaiser Permanente Hospitals in Northern California showed that older mothers (40+ years) were 30% more likely to give birth to a child with Autism Spectrum Disorder (ASD) (1 in 123) than younger women (25-29 years), while older fathers (40+ years) were 50% more likely to have a child with ASD (1 in 176) than younger men (25-29 years) (Croen, Najjar, Fireman, & Grether, 2007). Similar data were found for children born with Down Syndrome (Stoll, Alembik, Dott, & Roth, 2005).

While the effect of postponed parenthood may have a positive effect on socioeconomic status of the family, caring for a child with disability commonly

has a negative effect on finances of a family (Knapp, Romeo, & Beecham, 2007). The cost of caring for a child with disabilities is three times that of caring for a typically developing child (Järbrink, Fombonne, & Knapp, 2003). Families who have spent a lifetime caring are especially likely to suffer financial interdependence. In other words, their lives are economically as well as emotionally inextricably linked with those of their sons and daughters with disabilities. In addition, recent research of parents of children with ASD showed that 56% of the respondents were unemployed, while 24% were in part-time employment due to being the main carers of their child (Keenan et al, 2007).

In terms of family relationships, divorce rates in families with children with disabilities are estimated in the region of 82% (National Center for Autism Research and Education, 2008). Bromley, Hare, Davison, and Emerson (2004) found that one in three families of children diagnosed with ASD were headed by lone parents.

The Census (2001) showed that being a carer oftentimes had detrimental effects on training and employment opportunities. Of course, in order to enable family carers to study, work, or engage in leisure time activities they require child/dependent care arrangements. Finding substitute care, even if only short term, can be difficult, especially if specific specialised care is needed.

Major challenges for education and employment of family carers of all ages are the financial costs of caring, low expectations and even surprise that carers should wish to study or work, and poor information on financial support and care options (Russell, 2007). A combination of these factors leads to levels of deprivation and financial hardship which exceeds that of the average family in the United Kingdom. Given that Northern Ireland is one of the most deprived areas in the UK (Social Disadvantage Research Centre, 2001), the effects are compounded.

- **Personal and family issues**

Older people who are caring for an adult dependant son or daughter with disabilities are under tremendous stress (Australian Family and Disability Studies Research Collaboration, 2004). The impact of advancing age means that generally these parents experience more physical and emotional tiredness than other parents and are likely to suffer deteriorating health. In addition, they go through increasing anxiety over who will care for their child after they die.

Families who have spent a lifetime caring oftentimes experience a distancing from professionals and the service system. Service workers and professionals are not perceived to have the knowledge and experience to truly understand issues faced by older parent and carers. By-and-large these families are characterised by strong self-reliance, a reluctance to ask for help, and intense worry about planning for the future (Australian Family and Disability Studies Research Collaboration, 2004).

Bigby (1997) reported lifelong close relationships between siblings and their brother or sister with disabilities and found that nearly half of their sample had a sibling who acted as the primary carer after the death of parents. Although this was not considered a permanent arrangement, in the majority of cases the sibling took responsibility for well-being and advocacy of their sibling with disabilities and played a key role as mediator and supervisor.

- **Health, bereavement, and mortality**

While some of these families have two parents, many will be lone carers either through the death of their partner or marriage breakdown. They also increasingly face loneliness and loss of support from family and ageing friends who themselves deal with declining health or death. Robinson and Williams (2002) drew attention to the fact that few parent carers receive adequate needs assessments or help with proactive forward planning and therefore have to call on paid carers in crisis and emergency situations.

Ultimately adults with disabilities who live with their ageing parents will have to face bereavement. The death of a parent involves deep upset and grief, however, for a person with learning disabilities, the death of their parent means that they loose their main carer, who has looked after them all their lives and on whom they were deeply dependant for support, advocacy, love, care, and attention. The loss can be particularly difficult to deal with if the son or daughter with disabilities is not fully included in the subsequent funeral rituals and has to move house immediately (Hollins & Esterhuyzen, 1997).

- **Legal issues**

Many of the laws that aim to protect carers and persons with disabilities are neither well known nor widely applied (Robinson & Williams, 2002). In England, the *Carers and Disabled Children Act* (2000) regulates the relationship between local Councils, carers, and disabled children. It is based on the National Strategy document *Caring about Carers* (DoH, 1999) which outlined the aim to support carers in their caring roles and help them maintain their own health and well-being. This meant that local Councils are to provide services directly to carers.

In Northern Ireland, Health and Social Care Trusts either provide services and/or make direct payments, regulated in the *Carers and Direct Payments Act* (Northern Ireland) 2002, to allow carers to purchase necessary services. Other relevant legislation includes

- *Children (Northern Ireland) Order* 1995.
- *Chronically Sick and Disabled Persons Act* 1978.
- *Carers (Equal Opportunities) Act* 2004.
- *Northern Ireland Act* 1998 Section 75.
- *Health and Personal Social Services (Northern Ireland) Order* 1972 (amended by the HPSS (NI) Order 1991).

Prior to the *Carers (Equal Opportunities) Act* 2004, it was often assumed that carers would have to give up all prospects of education, training, or work (Russell, 2007). This is now no longer lawful. The *Carers (Equal*

Opportunities) Act 2004 does not stand in isolation. It builds on the *Carers (Recognition and Services Act)* 1995 and the *Carers and Disabled Children Act* 2000 as well as the *Disability Discrimination Acts* 1995 and 2005 (Russell, 2007). It ensures that carers have more opportunities, are enabled to make informed choices, and that housing, education, health, employment, and leisure are fully considered in assessments.

Of course, the *Human Rights Act* (Joint Committee on Human Rights, 2008) applies to all, carers as well as persons with disabilities. It warns that people with learning disabilities may be especially vulnerable to infringements of their human rights as they experience more barriers to an ordinary life, have less access to information, including information on human rights and independent advocacy, may not be aware of their voting rights, and may need support to participate in the local community. Three articles of the *Human Rights Act* are particularly relevant:

- Article 2– the right to life.
- Article 3– the right to be free from cruel or degrading treatment.
- Article 8– the right to respect for private and family life. (Russell, 2007)

Only recently, more emphasis has been put on the views, rights, and experiences of people with disabilities and their families (Grant et al, 2005). Their entitlement of human rights to freedom, respect, equality, dignity and autonomy are now acknowledged in the law (Joint Committee on Human Rights, 2008).

- **Ageing sons or daughters with disabilities**

The increasing longevity in the general population (from 1900 to 2003, life expectancy for men increased from 48 to 75 years and for women from 51 to 80 years) means that people with disability also can expect to live longer than ever before (National Center for Health Statistics, 2006). The ratio of people who reach retirement age and have surviving parents or other very old family members nearly doubled in the past 50 years; in 1950 for every 100 persons aged 50-64, there were 2 persons over 85 years, in 2000 there were 4 persons over 85 years, and by 2050 this number is expected to triple (DESA, 2001).

- **Health and disability**

It is now well established that disabilities are on the rise, although the reasons for this are unclear and both environmental as well as genetic factors are considered in the literature (Frombonne, 1997; Szatmari, 2003). In addition, individuals with disabilities are more likely to experience other health related issues, such as epilepsy, diabetes, and are more likely to experience mental health problems. For example, Bhaumik, et al. (2008) identified a total prevalence rate of 33.4% for psychiatric disorders in their study population of nearly 3000 adults with learning disabilities. Behaviour disorders (19.8%) and autistic spectrum disorders (8.8%) were the most frequent diagnosis in men and schizophrenia, depression, and organic disorders were more frequent in women. Over 60% of those attending psychiatric services without a mental health diagnosis also suffered from epilepsy.

- **Dependence and independence**

Robinson and Williams (2002) found that 89% of adults with learning disabilities lived in the community, supported by unpaid members of the family. 25% of these carers were over the age of 70 and were virtually unknown to services until there was a crisis.

A number of recent governmental papers, including *Independence, well-being and choice* (Department of Health, 2005) and *Improving the life chances of disabled people* (Prime Minister's Strategy Unit, 2005) point out the importance of futures planning. Clearly, assessments should to be carried out in a timely manner and undergo regular review in order to allow for proactive planning. To-date, failure of services to meet the needs of carers and adults with disabilities are endemic and crisis management is prevalent (Robinson & Williams, 2002).

Unresolved issues of family involvement, separation, and independence prevent parents as well as sons and daughters with disabilities from preparing appropriately for the future. Parents have to prepare to give up their active parenting role (Freedman, Kraus, & Seltzer, 1997), which is a stressful transitional stage for any family. Lack of concrete long-term plans only serves to increase anxiety and stress about future. Of course, the transition is also stressful for the individual with disabilities, especially if they are unable to fully grasp the implications due to limited intellectual capacity.

- **Housing and accommodation**

The shift from institutional to community care in the 1990s has led to more people with learning disabilities living with elderly parents than in the past (MENCAP, 2002). Yet, Smith, Tobin, and Fullmer (1995) expose housing as "the most emotionally laden component of future planning because the parents must acknowledge that their son or daughter may some day not reside in their life-long home" (p.487).

Parents frequently feel that the needs of persons with a disability are not fully considered by service providers and that they themselves are required to take on the role of advocate. Parents also voice concerns about the quality of care in alternative accommodation and the potential of a lack of communication with the person with disabilities (Robinson & Williams, 2002). In many cases, parents who have other adult children quietly assume that ultimately a sibling will take responsibility for the adult with disabilities but they often have not discussed this directly with the sibling in question (Heller & Factor, 1991).

Valuing People (Department of Health, 2001) "requires services to secure a plan for all service-users with learning disabilities living with older carers and promises them and their families more choice and control over how and where they live" (Bowey & McGlaughlin, 2007, p39). The Government's vision for people with learning disabilities across a range of services is based on the four key principles of *Rights, Independence, Choice,* and *Inclusion* (Department of Health, 2001). In addition more recently, the Governmental

paper *Valuing people now* (Department of Health, 2007) identifies five priorities for action:

- Personalisation.
- What people do during the day.
- Better health.
- Access to housing.
- Making sure that change happens.

Although *Putting People First* (2007) stated "We agree that there is a need to explore options for the long term funding of the care and support system, to ensure that it is fair, sustainable and unambiguous about the respective responsibilities of the state, family and individual" (p.1), the experience of many carers is still negative (Bowey & McGlaughlin, 2007). Similarly, independent living schemes are often seen as leading to less support mainly because carers worried about their son or daughter being able to communicate their needs appropriately (Bowey & McGlaughlin, 2007).

- **An interdependent relationship**

The most significant factor in the relationship between carers and persons cared for is the mutual dependency of the relationship (Walker & Walker, 1998). However, this dependency is not a static state, rather it is a dynamic process that changes over the lifetime of both the carer and the cared for. The ageing of sons and daughters as well as the ageing of the carer play an important part in their interdependent relationship. With failing health many of the carers themselves may require care. With increasing age, many of the sons and daughters may assert their rights for independence and inclusion in peer networks. Despite the fact that governmental papers (Department of

Health, 2001; 2005; 2007) asserted key principles, set priorities for action, emphasized the importance to secure futures plans and aim to offer more choice and control, this message has not permeated service provision.

Bowey and McGlaughlin (2007) explored the views of older carers (70+) of adults with a learning disability with regard to planning for the future. 55% of these carers were either not ready or unwilling to make future plans. The reasons for failing to plan may be that carers do not have a sense of need if they still have their spouse, that they fail to understand the timescales involved in arranging alternative housing for the looked-after individual, or that they lack confidence in the options available and therefore are unwilling to hand over the caring role. However, another reason may be that for some the relationships with their son or daughter were mutually supportive and that carers as well as cared did not want to relinquish this. Kaufman, Adams, and Campbell (1991) found that in UK 51% of parents had no firm future plans, Freedman, Krauss, and Seltzer (1997) found similar rates in USA, and Prosser (1997) confirmed that up to 71% of parents had made no future plans.

Of the parents who had made future plans, most were relying on sibling or other family members to care for their son or daughter with disabilities; only a few had made plans including formal residential care or support in the present family home (Bowey & McGlaughlin, 2007). Parents with close informal network of friends and family seemed to be less likely to have plans (Kaufman et al, 1991). Complex reasons why planning was delayed included guilt and

confusion about options, although where the level of care required was very high, planning was more likely (Freedman et al, 1997; Miltiades & Pruchno, 2001). Ultimately, Bowey and McGlaughlin (2007) asserted, “If service-users are to have real choice and control over how and where they live in the future, then they have to be fully involved in planning well before the need arises for any change to take place” (p.52).

Section 2: Services and support systems

Voluntary and statutory organisations provide a range of support services that intend to help individuals with disabilities to remain in the family home as long as possible. Where a parent can no longer provide the care necessary, or the son or daughter has chosen to live outside the home, there are also a number of alternatives to home-based services.

As detailed in the *Chronically Sick and Disabled Person's Act* (1978) and its subsequent amendments, provision of health and social care services for individuals with disabilities should be negotiated between the provider, the carer, and the care user. In Northern Ireland, the responsibility of providers is devolved to five Health and Social Care Trusts (Duffy, 2008). Care may be delivered through statutory or voluntary agencies, or through what the Department of Health, Social Services and Public Safety (DHSSPS) has described as *informal care*, or a combination of these. Care users can access these services through their key worker, usually a social worker or a nurse, who will co-ordinate the care package. The care user may be living in the family home, in supported living accommodation, in residential accommodation, or in a specialist unit that offers nursing care. The system is complex because individuals may need to access a combination of these options to meet their needs depending on their circumstances over time.

To simplify the details of provision, the range of services and support systems is described first for those living in the family home, and then for those who live elsewhere.

- **Services available throughout home care**

    - **Domiciliary care and direct payments**

Domiciliary care is mainly provided by a local Health and Social Care Trust, which may include personal care, nursing care, and the provision or specialist equipment, and assistive technology. This may be delivered through the Trusts' own domiciliary care teams or by private agencies funded by the carer/care user through the *Direct Payments* scheme, mentioned earlier. Other support measures such as *Meals on Wheels* and *Home Help* services are available to provide domestic services, however, these are means tested.

The issue of adequate domiciliary care is complicated through lack of registration. The Regulation and Quality Improvement Authority (RQIA) in Northern Ireland is the regulatory and inspection body for day care and domiciliary services for adults with disabilities. Under their regulations they are only permitted to release information on services that are on the RQIA Register. According to Mark Lynch (personal communication, 2008), an administrator of RQIA, presently this applies to only 6 day care settings who have completed all the necessary paper work, although a further 159 provider organisations have applied for registration of 316 day care settings and 303 domiciliary care services. The RQIA does not distinguish supported living

schemes that are presently registered under the domiciliary care regulations. Not surprisingly then information on suitable accommodation, support, and day care is very hard to come by.

- **Day care**

Day care or day support for adults aged 19 or over is frequently used to alleviate family stress and facilitate normalising activities (Black Molaison, & Smull, 1990; McConkey, 2004). Day care centres aim to provide a range of social, educational, and leisure activities tailored to the needs of the individuals, as well as specific therapies. Oftentimes, transport is provided from and to day care centres and individuals attend 5 days per week or less.

Day support centres should offer structured programmes for less dependent adults with learning disabilities or physical and sensory disabilities; these programmes should be linked to further education vocational training, work experience, paid employment, voluntary work, and social and leisure activities and sheltered employment. Yet, despite their acknowledged utility, McConkey, Slevin, and Barr (2004) noted that "[a]lthough research is limited, the evidence does suggest that centres under-perform in terms of the outcomes they offer to people with a learning disability" (p.105).

- **Respite and short break services**

Respite care or short breaks offer a temporary break in caring for families. This can take place outside the home in a residential setting or scheme provided by registered host families in their home, i.e., *Home- from-Home*, or

as a *Sitting Service*, where a respite worker will stay with the care user in the family home while the parent (or parents) can leave the house for several hours at a time. Although they are not widely available, both types of respite care can be a major support for parents.

MENCAP's *Breaking Point* campaign (2003) identified that accurate figures of availability and usage of respite and short break services were difficult to obtain, and estimated that 6 out of 10 families were either not getting any of these services, or services were so minimal that they did not meet their needs. In fact, the Government's Annual Report on Learning Disability (2003) admitted that only one in five individuals with learning difficulties who were known to Social Services were benefiting from short break services. Concerns also were noted in the Northern Ireland about "…services and facilities for young adults with special needs or learning disabilities, particularly those who are profoundly disabled and have complex needs. There has been a lack of age-appropriate respite care in Northern Ireland for many years" (Northern Ireland Assembly, 2006).

The *Caring for Carers* report (DHSSPS, 2006) acknowledged that breaks from caring are essential and recommended that,

> "A range of respite care must be provided to suit the needs of both the carer and the person being cared for – week-long, one evening a week, weekend, overnight, short breaks in residential care – different options will suit different people. Respite care should not be seen exclusively as alternative residential care. Respite could also, often more appropriately,

be provided by somebody coming into the home. There is also a need for emergency cover to be available, for example, for carer illness.' (p.24).

A year later, *Priorities for Action* (DHSSPS, 2007) stated improving respite care remained a target area for Health and Social Care Trusts and that by 2011, improved access to physical/sensory disability care should be available by "providing an additional 200 respite packages a year" (p 17).

- **Adaptations to the home**

Specialist adaptations to the home such as shower seats, accessible toilet facilities, bed-hoists and ramps may be provided by Health and Social Care Trusts for persons with physical disabilities. If recommended by an occupational therapist, *Disabled Facilities Grants* may be provided by the Northern Ireland Housing Executive, which will fund work to improve access or specific facilities. Adaptations that are requested to increase self-help, independence skills, such as the provision of a flatlet onto an existing home are not frequently funded. Grants are means-tested.

- **Intra-family support**

Informal care is defined by DHSSPS (2001) as situations where family or friends provide support. This may include supervision or simply company, shopping, personal care, financial advice, and help with associated paperwork. This support is usually willingly given and forms an important

factor in maintaining the cared-for individual in the family home rather than in alternative placements.

The sharing of care-giving between family members obviously lessens the burden on the main carer (Bowey & McLaughlin 2007), however, it tends to reduce active future planning undertaken by carers, because they expect that the family network will continue the support after he or she is no longer able to do so.

- **Alternatives to home care**

    - **Care and nursing homes**

Care or nursing homes constitute alternatives to care at home and are used mainly for individuals who are highly dependent and have high support needs. Health Trusts, voluntary organisations, registered charities, religious bodies, or private owners generally run care or nursing homes. They vary in size and services offered, from small residential settings to large purpose-built establishments. Residential care homes provide supervised living, usually with separate bedrooms and a communal living area, while nursing homes provide nursing care within similar settings, particularly for individuals with high-level health related needs.

Care and nursing homes generally specialise in caring for individuals with specific needs such as physical disability, learning disability, older persons, or mental health. Weekly costs range between £234-1,000, depending on the

level of care and facilities offered; for families on low incomes, costs will be met by the local Health Care Trusts, with a contribution from disability benefits, while others have to meet the costs from family resources and benefits. In Northern Ireland, care homes are registered and inspected by the Regulation, Quality and Improvement authority (RQIA).

There is little full-time care or nursing provision for younger adults with disabilities in Northern Ireland. In England, institutions like *Home from Home* (2008) offer individually assessed 1:1 and 1:2 supports for adults with learning disabilities in small residential homes. These highly specialised services come at a weekly cost of over £2,000.

- **Sheltered and supported housing**

Supported or sheltered housing schemes are constructed to standards specified by the Department of Social Development, which has overall responsibility for Social Housing policy in Northern Ireland. Supported housing is designed for younger adults, with small units and a supervisory system in place. Sheltered housing includes apartments, small bungalows, or maisonette complexes with Wardens and are primarily designed for the elderly, who may also have specific disabilities. Sheltered housing is provided either by the Northern Ireland Housing Executive (NIHE, 2009) or by voluntary organisations, such as disability charities or housing associations.

Folds and sheltered housing offer an alternative to home care for individuals with lower dependency and lower support needs. In Northern Ireland, over

250 organisations including registered social landlords, local authorities, housing professionals, pro-active tenants, individuals, and charities provide sheltered and retirement housing, mainly for older and disabled people. This sector is co-ordinated by a national consortium for sheltered and retirement housing, The Essential Role of Sheltered Housing (ERoSH, 2006).

In 2006, ERoSH launched a directory that contains contact details and information about services and facilities for each sheltered housing scheme in Northern Ireland. Through initiatives like ERoSH, awareness and understanding have increased about the role of sheltered housing within local communities. These schemes enable older and disabled people to remain within their communities and lead independent, supported lives for as long as possible.

There is little provision of sheltered accommodation for young adults with lower support needs and different definitions make it difficult to compare schemes in terms of service delivery. However, Fakhoury et al. (2002) found that compared with conventional hospital care, service users were more satisfied with supported housing, their general functioning improved and social integration was facilitated. However, while less restrictive and more independent, there were occasions when supported housing lead to loneliness and isolation. Floating support officers or other kinds of supports can help secure and maintain tenancies by delivering practical support and advice that are viewed as beneficial (Collins & McConkey, 2007; Mencap, 2003; Triangle Housing/Supported Employment, 2008; Positive Futures,

2009; Praxis, 2009). Communal living can offer accommodation, schooling, workshops, and even farming under the same organisational associations (Camphill Community, 2008).

For many carers, there will be concerns about the quality of care in alternative settings as well as problems of availability. In a study of residential care in Sheffield, it was noted that where differences in standards of provision were observed; "…smaller community-based group homes are associated with better performance and more positive outcomes than either hostels or hospitals" (Hatton & Emerson, 1996, p.28). The degree of differences in the quality of care and the costs can be noticeable to the extent that "for a significant minority of people, their quality of life is relatively indistinguishable from the quality of life of people in hospital" (Hatton & Emerson, 1996, p.28).

Section 3: Planning for the future: A ticking *time bomb*?

Family carers worry about the future but oftentimes postpone forward planning. Consequently, the resettlement of adults with disabilities from their family home happens only after a crisis, such as the serious illness or death of the main carer (Scott & Donnelly, 2008). Walker and Walker (1998) are cautious, however, to lay blame onto ageing family carers who are not planning well enough ahead, instead they regret that "many family carers do have serious misgivings about their relative leaving home... [due to]… dissatisfaction with the range and quality of care available, their belief that their relative does not want to leave, and their own inter-dependent relationship with their relative for companionship or practical or financial support" (Walker & Walker, 1998).

- **The international picture**

There is little research internationally on futures planning. *Forgotten Families* (HelpAge International, 2003) describes the difficulties of families where parents died due to HIV/AIDS and grandparents have to take over the care for their grandchildren.

Oliver, aged 65, who lives in Juba, Sudan with his wife, six children, and two orphans aged 4 and 7 year of age, explained their life circumstances:

> *"The children are in poor health and one has malnutrition. I can't provide the needed care because I have no money and none of my relatives or friends help me. Sometimes there has been no money and the kids are*

ill and hungry and I've felt I just wanted to leave" (quoted in HelpAge International, 2003, p.11).

HelpAge International (2007) piloted other projects, for example in Bangladesh that focussed on the importance of older people's participation in decision making especially in health and social care.

In New South Wales, Australia, Llewellyn et al. (2003) found that participants relied on their own resources and challenge simplistic solutions.

> "Heavy dependence on coping strategies that involve older parent-carers in relying on their own expertise and trusting their own ability to solve difficulties is evident. Alongside these self-reliant strategies is a heavy reliance on cognitively reframing their life situation to be more 'acceptable' than it otherwise might seem (or appear to outsiders) rather than using strategies associated with managing or alleviating stress" (p.22).

- **Northern Ireland context**

Caring for adults with disabilities generally is a complex issue and this is the case even more so in areas of deprivation and civil strife. In Northern Ireland, given the history of civil conflict and the subsequent lack of focus on issues other then the *Troubles,* heavy reliance on family and kinship networks have developed, specifically in poorer and ghettoised areas (Hillyard et al, 2003). Historically social services have been difficult to access in some areas (Darby & Williamson, 1978). The effects are still felt in many areas of social care provision. Little is known about the reality of caring for adults with disability in

Northern Ireland, and even less about future planning of older parents who care for their adult sons and daughters with disabilities (Krauss & Seltzer, 1993). In view of this, the research reported here had the following aims:

- To give a phenomenological account of older carers' experiences.
- To explore the epidemiology of older carers and their families.
- To examine service provision for families of older carers.
- To identify factors involved in caring and futures planning.
- To offer an interpretative, theoretical framework for the future.

Section 4: Methodology

- **Ethical approval**

Ethical approval for this study was granted by the Research Ethics Committee of the School of Sociology, Social Policy, and Social Work, Queen's University of Belfast (first author's workplace at beginning of this study); see Appendix 1 for participant information sheets and consent sheets.

- **Participants**

29 carers (20 mothers, 8 fathers, 1 sister) took part in this study, who cared for a total of 27 adult dependants, including sons (n= 15), daughters (n= 11), and one sister with disabilities (Table 1).

17 participants were interviewed on their own (2 of them were carers of two sons/daughters), while 12 participants took part in couple interviews (2 couples caring for two sons/daughters; 4 couples caring for one son or daughter). The average age of participants was 65.17 years (range 47-84 years). The average age of sons and daughters was 33.48 years (range. 12-59 years).

Table 1: Composition of research participants

Single interviewee; one son/daughter/sister with disabilities

	Carer	Age	Relationship	Cared for	Age	Disabilities
1	Mrs T	76	Mother	Female	35	Learning Disability, depression
2	Mrs D	62	Mother	Female	28	ASD; LD, non-verbal
3	Mrs C	74	Mother	Male	41	Learning Disability
4	Mrs E	61	Mother	Female	29	LD, limited speech/ mobility
5	Mrs K	74	Mother	Male	42	Learning Disability
6	Mrs S	47	Mother	Male	18	ASD, Learning Disability
7	Mrs M	79	Mother	Male	47	PKU, epilepsy
8	Mrs F	60	Mother	Female	38	LD, Mental health
9	Mrs B	60	Mother	Male	33	ASD, epilepsy, depression
10	Mrs O	75	Mother	Male	44	Down Syndrome
11	Mrs G	80	Mother	Female	54	LD (not diagnosed)
12	Mrs Q	60	Mother	Male	13	Down Syndrome
13	Mr A	84	Father	Female	52	Cohen's Syndrome
14	Mr S	61	Father	Male	32	LD, cerebral palsy
15	Mrs H	66	Sister	Female	59	Down Syndrome

Single interviewee; two sons/daughters with disabilities

16	Mrs G	60	Mother	Male	28	DownSyndrome
	""	""	Mother	Male	24	Down Syndrome
17	Mrs Y	70	Mother	Female	34	Stroke, Aphasia, Epilepsy,
	""	""	Mother	Male	29	Down Syndrome,

Couple interviewees; two sons/daughters with disabilities

18	Mrs E	62	Mother	Male	41	Muscular dystrophy
19	Mr E	68	Father	Female	12	PKU, cerebral palsy
20	Mrs Q	60	Mother	Female	23	Deaf, blind, cerebral palsy
21	Mr Q	66	Father	Female	28	Learning Disability

Couple interviewees; one son/daughter with disabilities

22	Mrs K	60	Mother	Male	30	Prader–Willi
23	Mr K	61	Father			
24	Mrs L	60	Mother	Female	25	Microcephaly, cerebral palsy
25	Mr L	60	Father			
26	Mrs V	60	Mother	Male	40	ASD, Wheel chair
27	Mr V	65	Father			
28	Mrs Z	59	Mother	Male	25	ASD, Challenging behaviours
29	Mr Z	60	Father			

- **Research tools**

A semi-structured interview schedule was designed for the purpose of this study (Appendix 2). Using open-ended questions enabled participants to become active partners, tell their stories in their own words, introduce new topics, and add their interpretations of events, experiences and views. The

initial interview schedule was modelled on similar tools used in previous studies, such as the Carers' Assessment of Difficulties Index (CADI) and Carers' Assessment of Managing Index (CAMI) (Llewellyn et al, 2002). Questions and themes were adjusted to the Northern Irish context, where appropriate.

In addition, the General Health Questionnaire (GHQ-12; Goldberg, McDowell, & Newell, 1996) was used as validated measure of psychological health. The GHQ-12 is used widely in Northern Ireland and internationally as indicator of psychiatric disturbance. It is scored on the standard binary scale. It has a maximum score of 12 and a threshold score of 4, at which respondents are classified as *cases* or *non-cases*. Scoring over 4, and thus being classified as *case*, means that the respondent is likely suffering levels of tension, anxiety, and depression that have an adverse effect on their physical and mental well-being. In these cases, full psychological assessment is recommended.

- **Procedure**

Participants were recruited through convenience sampling using charities and support groups that work with persons with disabilities and their families. Support groups were identified using Duffy's (2008) contacts and expanding this list through personal contacts and recommendations. Initial contact was made by telephone, and where a group agreed to participate, interview dates were arranged with individual participants.

Interviews lasting 45-60 minutes were held either in the premises of the charity or support group or the family home (whichever was preferred by the participant). Interviews were tape recorded (where possible) and transcribed. Both researchers read the interview transcripts and identified themes and sub-themes. The GHQ-12 was completed by each carer independently, or read out by the researchers, depending on the participants' preference.

- **Analysis of findings**

Interpretative Phenomenological Analysis (IPA; Smith, 1996) was used for the main analysis. Using small samples and concentrating upon verbatim accounts, IPA focuses on understanding participants' idiographic experiences (Smith, Jarman, & Osborn, 1999), considering the dynamic processes involving the researchers (Brocki & Wearden, 2006), and balancing experiential claims against detailed and open interpretative analyses (Larkin, Watts, & Clifton, 2006).

IPA's two complementary commitments were used to structure the results section. The phenomenological analysis (Section 5) 'gives a voice' to participants. We deliberately report quotes comprehensively to make sure the reader listens to the voices of *older* carers, to ensure that they are heard *louder* and thus become *stronger*. This is underpinned by some basic descriptive statistics to illustrate the relative weight of particular findings. The interpretative analysis (Section 6) focuses on 'making sense', by providing conceptual and contextual commentaries and locates the phenomenological descriptions into a theoretical framework.

Section 5: Phenomenological analysis: 'Giving a voice'

- **Socio-demographics**

In view of life expectancy in the UK, i.e., for men 75 years of age and for women 80 years (National Center for Health Statistics, 2006), the age of the participants was crucial. 41% (n=12) of the participants were over 65 years of age (mean 65.17; range 47-84) and all of the sons and daughters with disability were under 65 years of age (mean 33.48 years; range. 12-59 years).

Most of the participants owned their own home (93%; n=26), while others stated that they lived in rented accommodation (7%; n=3). Although data were not available for all participants, there was some bias towards those who lived in rural environments (34%; n=10) versus those who lived in urban areas (14%; n=4). The average home size was 4.2 bedrooms (range 3-6).

Some participants had made no alterations to their homes to cater for the needs of their son or daughter with disabilities (24%; n=7), while most had made alterations (76%; n=22), such as fitting an extra bathroom, shower, or en-suite, fitting ramps and handrails, or fitting a wheelchair hoist.

> *"We had some renovations done about 12 or 14 years ago and we always intended to do some other things… Those are on hold now… Now prices have shot up… and I couldn't have people in here now, I just couldn't, not this last year anyway and now prices have shot up so much, we couldn't afford it."*

"We can get wider doors, but we need to get the front done, for the wheelchair, there's a step up if we bring the chair in that way, we would need to do that, but at the minute that's where we are."

Most of the participants lived with their spouse (76%; n=22), while some lived alone with their son or daughter with disabilities (24%; n=7).

Respondents had an average of 3.9 offspring (range 1-9); 88 sons and daughters in total. The average age of sons and daughters was 34.7 years of age (range 12-55 years of age).

- **Everyday positives**

Participants expressed that the most positive things in their lives was their family and their sons and daughters (51%; n=15).

"Seeing the children graduating from college and our daughters wedding."

"For me, looking after the family, especially [names of daughters]*."*

"My family – seeing my grandchildren grow up."

"Well, looking after [name of son] *is the most positive but I would like to do something for myself, some little thing…"*

"Just, you know, that we still have [name of son] *really, you know, again it's not really that positive, but, you just get on with it, you don't think about it, to be honest with you…* [name of son] *is there, we're here and it's our job to look after him you know so… that's you know, again it's down sides you're talking about, it's getting out, getting a sitter… stuff like that... every day* [name of son] *goes to* [name of centre] *that's the day centre... which gives us a break… that's positive... I can't think..."*

"For us, the positive side of it is that [name of son] *is in the best of health... he actually seems to be doing things he has never done until now he seems to be maturing now at the age of forty a wee bit... those are the things for* [name of son] *but for us personally up until now everything… you're talking about be negative rather than positive."*

Others mentioned health, work, sport, social support, and general attitude to life (48%; n=14).

"Enjoying the first year of retirement."

"Work, [name of son]*, United winning the league."*

"[name of home help]*, she looks after me, she's my chauffeuse, and looks after all my paperwork."*

"Most positive? Everything I do, everything means a lot to me. Being able to cook, being able to walk as well as I am, I'm thankfully not in a wheelchair, I'm able to do as much as I can do which is quite a bit."

"At the moment actually, the most positive thing is that we've agreed to be positive… we've come out of, we've quite an… uppy-downy spell, Just, you know, that we still have [name of son] *really."*

However, others expressed their worry about the future, even when talking about the positives in their lives.

"…I'm not positive about anything, I just take each day as it comes and make the best of it and… I suppose, I have asked the social worker about finding suitable accommodation for [name of son] *prior to my decease… I would like to think that he would be dealing with that at the moment, it's actually a year since I asked about it because I don't want to leave a burden for someone else and I want to ensure that there is a place for* [name of son] *where he will be contented and in an environment… you know, suitable for him."*

"We take holidays and do that instead of smoking! We decided to give up for [name of daughter], *we wanted to live as long as long as we could, to look after* [name of daughter] *you know."*

"The thing is, as we get older you do think what if something happens us, what will happen to [name of son]*… which is why you're here, I*

suppose… my daughter says 'Don't worry Mummy I'll look after [name of son]*', but I don't want her to. I don't want her to have that life that I had, and then again, I really don't want him in a home, so I just hope, I hope that God will take him before he takes us, but that's not always the way, so you have to think of these things."*

- **Everyday challenges**

The greatest challenge in life for many participants were their son/daughter's care requirements, the need to keep them occupied, and difficulties in dealing with behavioural problems (48%; n=14).

"Finding people to help care for my daughter."

"Always have to be available for supervision, no free time."

"One of the biggest problems I have with [name of daughter]*… we have a wee grandson, and* [name of daughter] *doesn't like him. She is very, very jealous. We had a wee dog for years and* [name of daughter] *never ever, ever took to that wee dog. The minute she seen the dog... and the size of it, it was only a wee one, as soon as we came in the door with it, she said 'uh, uh' and she's doing the very same with this wee grandson. As soon as she sees him, she's shouting and she's so placid, she's such a placid wee girl. Now, I have been down and seen a psychologist a couple of times and she's told me to give her presents and say they're from* [name of grandson] *and we have the naughty chair... we've tried everything… and it's not working. We know exactly what it is, it's just*

jealousy, because [name of daughter] *had our full attention and now this wee one's come along…"*

"…there are things he doesn't like. He does not like taking a shower and there's a pushing and shoving match and the roars of him sometimes… and I'm always waiting 'til he breaks something. The shower equipment isn't that strong and [name of son] *is a big, strong… and he refuses at times; 'come on* [name of son]*, shower' and he's –'No!'"*

"Well, I don't dwell on it… I don't dwell on that. We have carers as [name of husband] *said, carers coming in every day, three times a day, it's an intrusion in your life. If you have your dinner at a certain time… so you're eating after 8 o'clock, or you're eating earlier when you don't really want to, so there's a lot of negative things, but again we can't get rid of the carers because there might come a time when we can't… we can change* [name of son]*, if we have to, if it's a necessity and the carers aren't here… but my daughter, she would help as regards letting us out for a night or stuff like that but there's a lot of negative… more than positive."*

"Well, [name of son] *is here, we are in a situation, and being in a situation,* [name of son] *is not particularly difficult you know. Everything in life is going to be compared to something else... compared to other people in the same situation. We're quite lucky.* [name of son]*'s fairly easy to look after and that, you know, but it's very difficult to see any*

positives… that come from the situation... I've found that the coping mechanisms I would have myself, like golfing… or social things have all sort of dwindled…"

"Our own kids were always reared to think of family first… that sounds great when you're rearing them and you know they're all at home... but I've begun to think of this over… the last 20 years really... you're also putting pressure on them, you may not realise at the time, pressure for looking after [name of son]*… That's not what you meant to do but you wind up because you have… those values are there, the family look after each other, if you do go drawing on the skill thing… I don't think if you were talking to anyone else they would be aware… maybe other people aren't aware, but we're quite aware that's what we've done…"*

Others worried about future planning (10%; n=3) and their own health and wellbeing (24%; n=7), and work (n=1).

"That is probably my one challenge... it's a big challenge, it's going to be a problem in the future you know, finding a place… suitable."

"Our biggest problem, as far as both [name of son and daughter] *are concerned, is how long are we able to go on? We think a lot about that… and we haven't come up with an answer. Because, our health could change, overnight."*

"Where would you start… in the last year we've had an awful lot of problems with ill health, that's my ill health. The little bit of respite we had was taken from us because the rules had changed. That made things difficult... with [name of husband] *looking after the children when I was in hospital, taking them with him when he was coming to visit…"*

"Managing the behaviours that my two sons with learning disabilities present with, [name of son]*'s behaviour, sleeping, and not being as well as I was myself.*

"Having not enough qualifications, not having any qualifications, I stayed at home and reared my children… worked on the farm… I wouldn't have any qualifications."

"Well, if... and it will happen some day maybe, if we go before [name of son]*, I would think my son in America would come home and look after him but even again, I don't want to say that, for that would put pressure on his marriage, and* [name of daughter]*'s here in* [name of town]*… and because we both come from large families, the large family was common... we had a family of four which is fairly standard, you find that you don't have the spread… the burden… ours are spread throughout the world, the only two at home here would be* [name of son] *and* [name of daughter]*, you know… but all the work that would be shared in my case with five or six sisters, with my family, with my mother and father, is now on* [name of daughter]*'s shoulders. And* [name of daughter]

unfortunately is the one of the family… who is sensitive and will take it all on board…

"It can be scary at times because you do think… you think, what is going to happen… you know when we do go, hopefully, I'm not wishing for [name of son]*… but I hope that God would take him before me or* [name of husband]*…"*

"I'll take the cards as they fall, it doesn't matter to me, but [name of wife] *was staying in* [name of town] *there, and* [name of son] *was in respite, Thursday night was the first night in years that I had been by myself and I couldn't think of anything to do... as free as a bird and I couldn't think of anything to do and I got myself in really bad form... but my daughter called in… on her way back from work and it was only the next day she was saying to me how scary it was, you know coming in and no noise…"*

"*You see when* [name of son] *was given to us, he was given to us as a normal child, then a year later I'm sitting in an office with a paediatrician and he's telling me we'll look after him 'til he's 5, if he survives that. So, I mean, he's 40 years old now and 40 years is an awful long time!"*

"We have a friend... he's a retired headmaster... he came in one day and started, have we thought about the future and what's going to happen to [name of son]*… of course we've thought about it, we haven't done anything about it yet but he was saying you have to think about it.*

There's a place down there where he can live independently and I said '[name of son] *has to have somebody, don't even go there, I don't want to know'. It's all very well him saying there's places in* [name of town]*, there's places here there and everywhere for* [name of son] *in the event of our death but* [name of son] *is dependent for all his needs, he can't... I said 'don't go there', not because we don't want to plan for* [name of son]*, of course we do, but it's just…"*

"I know there have been a lot of negatives… but [name of son] *is not a burden.* [name of son] *is ours, he is our son, number 1, and we want him… when he was 5 or 6 we could have left him in* [name of special needs residential unit]. *We are aware of the options that were available... what does niggle sometimes is they would say…* [name of son]*'s care is maybe 5 or 6 hundred pounds a week… it works out more like 5 or 6 hundred pounds a day to look after someone like* [name of son], *if he was in full-time, you know? A lot will depend on your own personality, are you a good planner, you know… we do see the problem but part of it is you don't want to recognise that this may happen, so you just delay thinking of it. If you started thinking about it you could think yourself into making yourself ill… it would affect your relationship with* [name of son] *too…"*

Home carers while mainly thought of as helpful were considered a challenge by some.

"Carers… become, you know, an awful wearing, they wear you, if you have two people coming into your home 3 times a day, your whole day is timetabled around carers. That plus [name of son] *is, himself... he is quite demanding, not severely mind you, but he can…."*

Others continued to think positively even in face of adversity.

"I really am lucky… I'm still working, I have a shop in [name of town] *which is a lot of therapy or it was at a stage, I'd been in the house so long, it's not a problem because* [name of husband] *has retired and he's here with* [name of son], *so I would say I just take life easy but I would be anxious about* [name of son]*'s future, you know?"*

- **Relationship with son/daughters**

For the most part, parents described their relationship with all their sons and daughters with love and affection (79%; n=23).

"Excellent – enjoy spending time with them when they are home from college/visit me.

"Very good – family that live near me visit several times/week and we speak on the phone. I go to some of my children's houses every week for dinner on Sunday."

"I'm glad they're not here! [laughing]*. Well they're awfully good to me but they do wind me up… make fun of me all the time, but good friends I*

would say, you know? If they were here, they would think that was a golden opportunity."

However, some parents described difficulties in their relationship with their sons or daughters (14%; n=4).

"Difficult at the moment, was better in the past, a lot has changed since my husband died."

"Generally good but we have the occasional fallouts."

Other parents realised that is had been difficult for their other sons and daughters to grow up with a sibling with disabilities.

"Well, I suppose [name of son] *really, was always the central point in the family, which I suppose wasn't right, in that my daughter was always such a good baby; she more or less was left to cope!* [name of son] *didn't walk until he was nearly 4 years of age and his diet was pretty difficult, but I would say that my daughter is probably similar to myself in nature and she kind of gets on with things."*

"Oh, I don't know… the boy's an alcoholic, he was doing very well there, but he's broke again... The daughter in [name of town]*... a lady this morning told me how good she is at her job, I said well she's very conscientious, it's good to hear that…"*

- **Care provision**

Parents provided for the majority of care needs. For most parents caring for their son or daughter with disabilities was a full-time job (90%; n=26).

> *"Any given day, you've 24/7 care and I mean 24/7 at the weekend, during the week that time that* [name of son] *is away, I'm on call…"*

> *"You would actually have to get in there and do it yourself, you know, have to end up doing it. He would have a wee go but he would just sort of rub and then you would say 'what about under your arms' and the same with brushing the teeth, he'd just sort of sit there with the brush, so you'd take the brush. Constant supervision or constant prompting, you know? He wouldn't have any idea of cooking or making meals, or travelling, going out on his own or coming back on his own, you'd have to be with him… he has no speech…* [name of son] *has absolutely no speech."*

> *"Well morning noon and night revolves around him, he is an absolute priority, and that's not a problem!"*

> *"You never measure this in time, I'm sorry if that sounds evasive… but it is just daily life… and she comes in through the door with a smile on her face 'hello Granny' she calls me Granny because the grandson's here and I don't correct her, she knows I'm her mother!"*

Some of the parents considered it respite, when their son or daughter attended a day centre.

"Well, it takes up a lot of time in the morning about an hour and a half in the morning then when he's there at half past 3, you're with him all evening. At night, he doesn't give me any bother but at the same time…"

Only one of the participants' sons lived away from home but spent the weekends with his parents. Yet, even these parents spent a considerable amount of time on his care needs.

"I mean, he comes home to us at weekends, Saturday, Sunday, we look after him then I would spend maybe another half day a week managing his carers and his schedule… finding things he's left behind mostly!"

Much of the care provided included looking after physical and health care needs of the son or daughter with disabilities, such as help with getting washed, dressed, fed, having medication administered (86%; n=25).

"Both boys require 24hr supervision; personal care… dressing, personal hygiene; meals prepared, medication administered and monitored; clothing washed; activities organised. Similar to the type and level of care a 3-4 yr old requires."

"[name of daughter] *requires verbal prompts while dressing and needs assistance when choosing clothing to ensure they are appropriate to environment.* [name of daughter] *requires supervision at all times, both within and outside the home. She can assist in the preparation and*

cooking of meals but cannot cook independently. [name of daughter] *needs someone to administer her medication.* [name of daughter] *also relies on others to organise her day for her."*

"Well, [name of daughter]*… she can do so much for herself. I've got to help her shower, I've got to make her food for her, she can eat her food herself, I've got to see to her personal needs, she can dress herself to an extent but you've got to go and correct that, so I don't know what band you'd put that under…"*

"24-hour care really. [name of son] *would need help, a lot of help, with his personal hygiene, all of his meals cooked for him, and if you leave out his clothes he can dress himself but you have to pick the clothes for him. He couldn't go to the wardrobe and choose trousers and a top… whatever I leave out for him… should I leave out a dress he would put it on and go out in it!! So all of that needs taken care of, all of his personal hygiene, shower, wash his hair, brush his teeth… he would make efforts to do some of that himself and we would encourage him…"*

"Well, he needs hygiene care quite a bit of it and that is one thing, I have heard… it's the same with older folk, they don't want to change their clothes either. It's a battle royal with what we call 'u.p.'s, an absolute battle royal and then you get a really good period where he has his own system, then it's under the bed, or he'll tell you they are clean… now that is something that's returning. He was in nappies for years, but maybe it's

my fault. He was in nappies until he was 12 but I knew no better… Well, he was the first, and the others trained themselves… Anyway, constant supervision and for two reasons and you would appreciate this… he has reached the stage now where he considers he is independent and he's an absolute shopaholic when he gets out. He is a disaster with traffic, an absolute nightmare. The other thing is, and he comes to [name of town] *with me quite often, one or other of us is always with him and that's aggravated by the lack of speech or the fact he chooses not to use the bit he has, which is 'coke', 'cake', 'fish', and '*[cuss word]*'. Now he never says it to anybody but he says it in the bedroom '*[repeated cuss words]*'. I can only imagine he's copying a row he heard at the training centre, but I would open the bedroom door and say 'is that nice' and he's going* [laughing sound], *'don't catch me'! He's a born communicator but I would not like, in the world we live in… I always take him to the ladies toilet. I don't think he's vulnerable really, because I had one incident, and I'll tell you now it terrified me, I'll tell you why... I can be flippant but he has been the laugh and the light of our life and if anybody laid a finger on him... watch this space for I would swing for them!"*

"Personal care, now she doesn't just clean up very well. There's always a problem with that and I have to wash her hair and comb her hair in the morning. She has very thick hair… you just see to her, I'm up every morning at quarter past 8. She's up at 8 and calls me and leaves the house at a quarter to 9. I had a back injury in 1991 and ever since that she makes her own breakfast, she's very good... we set everything up,

the porridge and the microwave… she sets the table every night herself for the two of us, porridge or cereal, whatever she wants, she knows where to get it, the milk and she can boil the kettle… anyway, she can manage herself, and I'm up to see her out."

At the same time, providing supervision and appropriate activities dominated the care needs for many.

"For [name of daughter] *more of supervisory care. Let's see, and companionship maybe when you consider her friends; she has a few friends from her school days, and those are her friends now. A lot of them left her after she had the stroke and dysphasia, she wasn't speaking and they cleared off because they couldn't hack it, but she has three, maybe four good friends and of course her best friend died of cancer about a month ago. She took breast cancer after her first child was born and she died there leaving three children. She was the same age as* [name of daughter] *and that took a lot of getting round."*

"We would really ensure his safety, would that be the best description, we would make sure that he's safe and doesn't have access to food... uncontrolled access to food."

- **Positive aspects about having a son/daughter with disabilities**

Most parents identified a range of positive aspects of having a son/daughter with disabilities. They enjoyed the company, spending time together, and going out (79%; n=23).

"The most positive thing about the care we give him… well, I suppose it would have to be that he know its us giving it, although he doesn't have any speech you know he's happy he's at home with us… you know he's happy even if he can't say… you know by his reactions… when he goes to respite and you go to collect him. A big smile, and coming from the Day Centre, a big smile and you know one of the most positive things is that he's at home…"

"He's a joy to be with, isn't he? I think he has become very contented with his lot, and he's relatively easy to… once he goes to bed that's it and he sleeps right through the night."

"Because he's so kind and so pleasant and doesn't create any difference between… loves Mammy, loves Daddy, loves everyone and you wouldn't change him for the world!"

For some, having a son or daughter with disability was making the loss of spouse more bearable.

"…he gives me a routine since my husband has gone. I've no other family. He provides routine. Actually, I would say that he is probably my reason for living at the moment. That sounds very flat... very negative!"

Some participants could not see a positive side mainly due to lack of support, while others found the support they received positive in helping with the son or daughter with disabilities.

"…I've been caring for her for years… it seems like years, you know… lots of the time I feel as if I'm hitting against a brick wall because the Centre she goes to, I don't feel they do enough to try and help. Nothing much happens there. A lot of the time it's quite frustrating because I feel [name of daughter]*'s capable of a lot more but the services don't seem to be there to get it to her so… I suppose the positive thing has to be in the social times where you know we would go to* [name of town]*… social time together, that's it."*

"The respite… We had two weeks then, four or five times during the year; a long weekend at Halloween… She was away for two days there a couple of weeks ago, you see you get up in the morning and you really miss her you know, you really do!"

"As regards her work in the hotel, if the hotel owner had all his workers as eager to get down to work… She sits here in the morning with her chair turned round so she can see the bus coming, and if it's late she looks at the clock. 'I can't be going into the hotel late!' We don't have a mobile any more, we needed a new one and I can't afford it, but we get away. We have a holiday. We went to [name of town] *last year."*

- **Challenges of having a son/daughter with disabilities**

The greatest challenges of having a son or daughter with disabilities were the lack of respite, dealing with difficult behaviours, including physical aggression, and meeting social needs, such as keeping him or her occupied (86%; n=25).

> *"Find it very difficult to get someone outside my immediate family who can manage* [name of daughter] *even for a short period of time, so I can go shopping, socialise etc. When I do find someone, it takes a long time for them to get to know* [name of daughter]*."*

> *"Managing their behaviour; always having to be available to go and get them if needed, e.g., from day-care, respite… never have a day off."*

> *"*[name of daughter]*'s behaviour. Quite difficult at times… quite difficult at times...* [name of daughter] *likes a thing to happen when it should happen, but that's not life… I had to ring them this morning to say… she could focus the anger on somebody, maybe they haven't done anything, maybe it's how* [name of daughter] *feels, like this morning one of the carers was going to get a slap up the face off* [name of daughter], *so I had to phone them to make sure they were prepared for that and direct her somewhere, distract her somewhere else you know… you have to be ahead of* [name of daughter] *most of the time."*

> *"He can be a bit of a maverick… He could strike out on his own in situations where it could be dangerous. We've had situations where he's gone walking, or taken taxis to places. He's very high functioning at that*

level and he could talk people into doing anything for him, so that to me is the danger…"

"He's awake listening to his music 'til 3 or 4 in the morning and he would get up and he is so friendly that we used to get a lot of people calling. We have an antique shop and friends and dealers used to come but you'd need to be careful who came to the door because he'd bring them in, all these people were welcome… we were always here… you could leave him now for half an hour and go down the garden for he's going to be playing his music for two hours, and see him from the back window. He used to wander when he was small, but if he wandered now he would think he had a purpose and that's what terrifies me… He would go off and no traffic sense whatever."

"Well, I would say personal care really from my end of it. She can sort out clothes and she can do a lot of things but there's things she can't do. I don't know if she could go out to a bungalow… Outside town there are four little bungalows… they're supervised, those girls… at the same time that's why, but I don't know …"

"We go to [name of town] *occasionally, again it's very occasionally we would have the opportunity to go up for an opera or musicals... he's mad about musicals, every kind of music at all. You see we can't go to* [name of town] *any more, since my husband died, I don't drive. This is very limiting too and there isn't a late bus back even if there is a symphony*

concert on there, so my only opportunity is, I have a niece in [name of town] *and she's very good. She has no children as yet and makes us very welcome but you know, you don't like to go up very often for she's working all day and so is her husband and* [name of son] *and myself... we cater for ourselves more or less, I don't like to think that she would have to cook, that way, and we try to use even her sleeping bags rather than her beds to save her… you know what I mean? I hate... I really hate imposing on anybody! But it's the only way... really the only way... we could ever get to theatre. Well, that's maybe a wee bit of an exaggeration for we have a theatre now in* [name of town] *and we have been there quite a few times you know… not the same opportunities…"*

Other parents mentioned that they had no time alone and were unable to do what their peers do at their age.

"Time alone together... that's what it is. I can't believe, we have 168 hours a week with [name of daughter]*. Even when she is at the Centre, we can only be out after10 and have to be back at 2.30."*

"Well, I wouldn't say there was a big problem to be honest, it's just that you have to be dedicated to his care and to me it's not a problem but it leaves you that you haven't your freedom to go where you want to go you know."

"For me the main negative is firstly the carers and the timetabling, and secondly, when in this day and age, when people have reached the age

of 60, 65 they've got family away. They can start a new life. We can't go out shopping even without considering… it's difficult you know, you've got a forty-year old man and a four-year old baby in the house… It would be silly to say, it doesn't affect you because it obviously does affect you… You just don't have the freedom that all your peer group does…"

A number of parents expressed their worry about the future.

"My problem for both of them is when I'm no longer here, who will do it? And I think for both of them, they'll need somebody. Well, [name of daughter] *goes out and socialises but she has never met anybody that you would think… She needs to meet somebody that would be trustworthy…"*

"At the moment there's no big challenge, we can manage him quite well, but in the future you'd like to think… If something happened to us and we lost our mobility or if something happened to [name of son] *and he lost his mobility and we were older would we still be able to care… It wouldn't be the worry now, at the present…"*

- **Family, social, and agency support**

For many of participants, family support played an important role in caring for their son or daughter with disabilities. 69% of the participants (n=20) received support from bothers, sisters, sons and daughters, and in-laws, and even their

own parents, however quite a few of the participants did not have any family support (31%; n=9).

"Oh yes, I have a sister and her husband would come and let us out... again we'd be back early, we wouldn't be staying out late."

"No. I don't have any sisters and my mum's dead, and I've only one brother, which I don't see that often… they phone, they phone… and [name of husband]*'s family are all…* [name of husband]*'s the youngest of the family, they're all older…"*

"No, unless we were going out and we'd ask some of them to sit in… it's just me and my husband and we do all the work with him."

"I haven't any neighbours... here, where we're living… I have an ex-neighbour, she was marvellous when we lived there... but… I think a lot of widows find this... when you have a partner you're more… I think people are more likely to ask you out for a meal, do you know what I mean? You're not part of a couple any more… if you have three couples, even if one or two are special friends… right enough they're very good about asking [name of son]*… things change… it's made a difference because I had friends and I could have gone out with hem and socialised and left* [name of son] *with my husband… now that's gone… and I had a sister who was more than good to me but she… is no longer alive… when my husband wasn't well enough to drive, she came here maybe twice or three times a week to take us out in her car…*

you can imagine two big… just two big slices taken out of our lives… [name of son]*'s and mine… I may sound down but I'm not because I don't even feel down, I try to make the best of each day but* [name of son] *is really what's left to me and this is why I'm trying to be unselfish and find a good home for him... I don't particularly want him to go into… it sounds awful… a social services run place. I know two, and they're probably all right but* [name of son]*… has missed his daddy terribly… and I suppose* [name of son] *is a companion for me at the moment... do you know, that sounds ridiculous doesn't it?"*

"[name of son]*... goes to* [name of day centre]*, Mondays, Wednesdays, and Fridays. He loves going... on Mondays he goes to the Tech to do cookery... that's where he's been today. I don't think it entails a lot of cooking… maybe Krispies into wee cups... chocolate Krispies and today he made sandwiches, he brought sandwiches. I think it's just the relationship he has with the little tutor... I think there's just a small number of them... I went out to collect him one day and I hadn't realised that the atmosphere's so peaceful and quiet, she's gentle and very quietly spoken and they relate to each other very well. Wednesday's not so good, it's hit and miss sometimes he gets a trip into town to consult the bank, or shop, but they sort… Wednesday's he comes in and he's not so good. Thursdays he goes to the pool with the group... again it's a small group, go to the pool."*

Only a very small minority of participants received help from friends or neighbours (14%; n=4), although this was partly due to the fact that they did not ask for help.

> *"No, but we've never asked them… I'm sure they would, if we asked them… but we've never needed any occasion to ask them because if we're going out we would usually take* [name of son] *with us and if we were going away on our own for a week or that, we would use respite."*

> *"They all did their bit for 20-25 years… I've somebody comes up during the day for a few hours and he adores the ground he walks on…* [name]*, she's a great help, and the girl who helps me in the shop, they understand him. The girl who helps in the shop, she used to come up to baby-sit with him when he was young and she's a grandmother herself now… I've good friends I must say."*

> *"No, there's no neighbours around here, there used to be an old neighbour over there, when the children were small and you wanted to go anywhere you'd have wheeled them over in the pram but you wouldn't have left them very long with them. Two old sisters and two or three old brothers lived there. They were certainly not used to small children! As long as they were still in the pram it was all right, they wouldn't have lifted them out or anything, they just kept an eye on them. It wasn't very often anyway."*

In fact, some of the participants set up a specific support groups.

"…4 or 5 years ago I did take the step of creating a circle of support… I learned for the first time, instead of bearing it all myself, to go out and say, 'Can you help'. So my sister, and sister-in-law and Nanny became what we call… and they're involved with [name of son]*'s care and if we want to find out what he's thinking, we would bat things off them… If we want to find out what* [name of son]*'s feeling, they would share. He has very close communication with all of them, so it doesn't just depend on me, but I did set that up… out of desperation…"*

"…all this socialising he's doing nowadays, because for years there was nothing, my oldest boy started up the Down Football association... we have a very active Down Group in [name of town]… *it's another fella takes it now, but for* [name of son] *that was the best breakthrough, going to that football, alternate Thursday nights. Now they have recently started a youth club for Down children, so now he has youth club the one week and football the next."*

For the most part, support with day-to-day supervision was considered helpful, so as to allow main carer to go shopping or go out for a few hours.

"Well if we wanted to go away for a day, and it's not often, they would come and stay…"

"Helps when someone is there to look after [name of son] *so I can get things done like my hair, shopping, doctors appointment."*

"…if I wasn't home for [name of daughter] *coming home at 3.30, all I have to do is ring the bus or ring the school and say, would the bus driver leave her off at Auntie* [name]*'s this evening. Then they know on Thursdays to leave her down with the other friend. So, I have two others if needs be, but everybody you know, is busy. There's no point in saying, except they're paid for looking after someone, no-one does this any more. The extended family is over, everybody has their own homes, even if their mother or father needs looking after, they can't come…"*

Day care and home carers seemed to be the biggest help for most participants.

"The biggest help… I suppose the carer who comes in. He's a nice bright fellow you know… [name of son] *gets on well with him, and just… days when you're tired, it's nice to have someone …"*

"Those two things… day care and respite definitely… it would be [name of day care centre]*, she loves going over, she loves company… and the respite is a big help… it's a lady looks after* [name of daughter] *in her own house, you know, because we did try* [name of daughter] *in… some place. This is maybe 15-20 years ago when she was very young, for a weekend when we went to* [name of town]*, and oh dear… she didn't like it at all. We phoned and we could hear someone screaming in the background... it wasn't* [name of daughter]*, but for 6 months after that we couldn't get her to sleep. She was traumatised, she was definitely traumatised for months and months, it was awful and we said we'd never*

do that again, so they did look for a host family, a nice lady and gent who lived up in [name of town] *but they've retired now, they're older than us… This lady's very nice, they have a wee bungalow…"*

"The fact that a handful of people understand his personality... you can always get someone to wash up, but it gives me a lump in my throat…"

"…that she's able to walk and be as healthy as she is and I'm very pleased and happy that she is like that and she's such a wonderful help to myself… she looks after me and reminds me to get paper… she puts out the bin every week and she knows which one…"

However, the biggest challenges included general supervision, medical care, and moodiness.

"Twice a year he goes on respite, a sort of camp, a respite holiday, but he has a lot of tummy [skin fold] *and he would come back red raw because they don't dry him properly in the shower, and he wouldn't know to say. His feet would need attention too. When he had the other catheter that was a problem too. His peripheral nerves aren't good, and he doesn't realise if he is in pain. Independent living would still apply but…"*

"Our biggest challenge is that we're getting old."

"Well, the Paediatrician said to me, you need to be thinking of yourself a bit more… you have two children, one with learning difficulties and the other with a lot of disabilities, and you're looking after your wife, and I'm 66 years of age. I'm sorry to be saying this…"

"Getting her ready… I am fairly strong but I don't know what I'll be like in another 5 years time, I'll be 65 then, or 8 years time."

"Trying to read him, trying to keep ahead with his moods. Has he a headache? Is he happy? Days when he come in and he's sort of… you know by his expression, there's something wrong and you're trying to think 'Does he have a sore stomach, does he have a sore head, does he have toothache?', you know. To me that would be the biggest challenge trying to read the situation with him all the time."

"Well, when she's annoyed it takes a little bit of time, when I say annoyed... Now the road was closed yesterday and they weren't at school, simply because she was working at the hotel yesterday… What about her pay? She knows money but she doesn't know anything about managing... She hands it over to me. You'd think I was standing waiting for it! But the disappointment of not getting to work… this road… why didn't they do it on some other day? Why had it to be on the day she works? It's hard to pacify her at a time like that. She gets something into her head, we digress quickly before she loses her temper… snow has a very big effect, she just can't stand it."

“It was done by the lassie… the domiciliary care worker who knows [name of daughter]*, for years... that was wheeked out in December and that was four hours a week… Now I want to state that* [name of daughter] *is NG feeding... fed with a naso-gastric tube... we were just told to get on with it! We took her out of hospital, about 5 years ago… and that’s the problem, apparently the domiciliary worker cannot be trained to do it, although she had been doing it for three and a half years, you know, then all of a sudden the rules changed, and the agency said she couldn’t do it any more... that’s where* [name of solicitor] *comes into it, she’s talking about the Human Rights Commission... We have given her our authority... official authority... to do this on our behalf… She knows how to go about it, we didn’t know, we had a meeting with people from the agency in January... there’s been nothing done since… just talking and talking, then* [name of solicitor] *has come on board, since then… she’s getting answers anyway... she knows how to write the letters... whether it’s the ones she wants or not… If it’s not the ones she wants, she’ll keep on… Well, she knew what to do and we didn’t. She was a solicitor herself, plus she has a son with learning disabilities… We’re very pleased that she’s on board... that keeps us going... if we had nothing… It’s great to talk to someone who knows what we’re talking about, and what we’re not getting… because she has got it all for her son... he’s not on naso-gastric feeding or that, but she has everything set up for him, and they see him at weekends… so that’s what we’re looking for, for when we’re gone… the district nurses won’t touch her tube, if it*

comes out they won't touch it… we offered to put a clause in, to say that we wouldn't hold them responsible… but it doesn't matter... at the adult training centre there's one person... one person... who is allowed to look after [name of daughter]*... and she goes on holiday this week, and a trained nurse has to come from* [name of town]*! If we were to get respite, she has to go into hospital, for nursing care… and she's not a hospital case… We wouldn't want the hospital situation… That's why we want this written down…"*

Participants generally found social service support helpful. Many of the sons or daughters with disabilities attended day care or were offered occasional respite care. Some parents had home helps for domiciliary support. Financial support was welcomed. However, four participants did not receive day or respite care, nor did they receive home help support.

"[name of daughter] *attends day care 10am – 2.30pm, five days/week. Previous attempts to provide respite and support have been unsuccessful due to* [name of daughter]*'s behaviour."*

"Purely personal care… an hour in the morning and an hour at night. It takes two since July. Respite is non-existent because of [name of daughter]*'s needs, really it would be hospital care."*

"[name of home help] *is here for 3 hours on a Monday, and the Independent Living Fund (ILF) is done through the Social Worker. It's put more stress on me… It's impossible to comprehend. You have to*

account for everything. There is no local respite, so [name of daughter] *has to go to* [name of town]*, which is 47 miles away; that's four trips, there and back twice, and with the cost of fuel going up… but you can't use the ILF money for fuel. I have to pay for the respite myself as well… there are carers for* [name of daughter]*. They come from 5 to 7 in the evening to get her tea and on Saturday morning from 10 to 1 to cook enough for the two days over weekend, but they won't do anything else. If they are ironing, they will sort out my clothes and leave them to one side* [*un-ironed*]*!"*

"I suppose having the financial assistance provided to us and put in our control. Direct payments… Independent Living Fund… Whereby we could determine the level of care, the carers and flexibility in how to manage [name of son]*'s care and still have him as a member of the family."*

"…what Social Services? He has the life of Reilly because he's mobile and anywhere he can go on with the Club or from the day outings… You were asking about Social Services. Oh, my head is only working again now… care, because of all these hours he's up at night, do you know, and if [name of husband] *didn't do that, it would be a major problem… you see he's a playful adventurous personality and he would try something …"*

"Social Worker? Yes, she has, but we haven't had occasion to use him. [name of social worker] *is that his name. Well, when she came back from* [name]*, well, I had to take her from there. I got her a place at the day centre at the time and they moved to out here and she goes as a matter of course, every day. She loves it."*

- **Care plan and review**

Most participants were either not aware of care planning or did not have a care plan for their son/daughter with disabilities (79%; n=23); although some participants referred to a care plan.

"No. And when I asked for it, I was told if I give you one I have to give everybody one…"

"We have a care plan, Social Services doesn't! We have a care plan which spells out exactly how [name of son]*'s care is covered. We have care allocation… we get paid for 96 hours a week and we look after the rest, which is about 67 or 68 hours I think. 24/7 who gets paid and who doesn't…, we rely on unpaid care, family and friends for the rest... Maybe 72 hours we cover ourselves."*

"Not really, except something comes out of this independent living, if I die, she'll maybe have to go into a home. I know my son couldn't look after her that's totally out of the question… and it's hardly fair on my daughter to leave her so she's the sole carer, she'd be maybe her guardian but for her to look after, she's her own life to look after…"

"Social worker has a plan, as do day care and college, annual reviews."

"I suppose I have... we have a meeting at the satellite centre, where we have a review. I could ask for anything... but seldom get it!!"

Many of the participants were aware of the need for change and adjustment to care arrangements over the years, although they did not always receive support in the implementation of changes (69%; n=20).

"As [name of daughter] *has matured, fewer services are available e.g. speech and language therapy."*

"It increased through dire need really. It changed after [name of daughter]*'s cardiac arrest. Then there was the transition between the two types of provision, education and health. Disabled child education provision lasts 'til they are 19, then: 'You're going over to the centre next year', but the transition was slow."*

"When his depression developed, I went to his community nurse, we have community nurses, and I said, 'Look, he's not eating'. He went completely anorexic. I was convinced there was something wrong with his stomach, for he really loves his food. I just never thought depression… [name of son] *wouldn't be very emotional as long as someone is there, it doesn't matter, he doesn't get emotional so I didn't think he could have depression. And there was nothing happened that*

changed anything… So right away the community nurse got him into [name] *Hospital where they did the tests and all. They sent to* [name of town], *so they could rule out any medical causes… They were really very thorough, they were. I suppose it was because I kept insisting. They did mention depression when he went in at first, but I kept saying: 'Don't be silly,* [name of son]*'s not emotional'… They were saying he doesn't have to be, but I wanted him checked out physically first you know… He wouldn't eat, he wouldn't drink… he wouldn't even swallow his own saliva… the lot. And he would have sold me for a bag of crisps six months before!! No bother to him!! That's how much he loved his food."*

"There's only been one [*change*] *and they responded… they wouldn't dare not!* [name of son] *decided he wanted to stay in town and do something on a Friday night as other young men do, so Independent Living Fund and the Trust came up with the extra funding… so he could go to the movies and play pool."*

"...unfortunately, if I had stayed here I would have been unaware that there were better things for [name of son]*. My husband was moved to* [name of country] *for one year when* [name of son] *was 7 and we changed hospitals and I found the most marvellous paediatrician, he was the expert on that condition and he recommended a school, which is a big hospital outside* [name of town] *with a school attached, a small school. They had brain-damaged children or children from operations… the fit children were able to wheel… they had a veranda and the door*

was open all the time. It was beautiful and they used the Montessori method. When [name of son] *was 3 or 4, I sent for the Montessori method, a great big book, but you know it was hard going for I had a new baby then and anything I did with* [name of son] *once I… I was very loath to send him out but I realised he had to go somewhere... he can no longer do the alphabet, he no longer do his name, he no longer can count, he no longer has the ability to do… I did a lot of those Flash Cards with him, that's all gone. I suppose I got lazy, but I was getting older and I had a daughter as well and I was part-time teaching… with* [name of son] *out to the centre, he lost the ability he had. I felt very bitter about it at the time because he wasn't… in* [name of country]*, he was entitled to Special Education but here at that time he wasn't. There's a school down there now… Special School and I and another mother fought for years, too late for* [name of son] *and for her son when it came about. It was available in* [name of country]*, if I had stayed here I wouldn't have been aware of the facilities which were available… my regret is that I left* [name of country], *but then again I had family here, my parents…"*

"…when [name of son] *was younger, before* [name of daughter] *was born, there was… he must have been the doctor in charge of children with a mental handicap as they were referred to then… he made arrangements for* [name of son] *to go in... it was the only place in* [name of town]*, it was over the shops… a crèche… and I afterwards joined a group of mothers. We used to run drives to raise money for this wee*

thing, and then it was taken over by the DSS, but the DSS really provided care, there was no education, they didn't have to anything… if they'd even trained them to tie their laces... [name of son] *can still not tie his laces... I spent… it must have been a year… before he went... to* [name of town]*... I thought it was great he's getting out… I had already taught him to do his buttons even though it took hours to put on his clothes. That's the only thing about the carer, if he's in a hurry, he would tend to do … too much for him, do you know? At least I have him at the weekends and I just let him do his own thing, you know. He dresses himself… but I think places like 'special care' took away any independence or any initiative they might have had. Now* [name of son]*'s out on his bicycle but before he's have gone out and dug a wee hole and done his putting... his daddy bought him a putter, and I remember him putting up cricket stumps... this is years ago... he lost all that. Isn't that strange?"*

"There is no stimulation and there's nobody speaks to them now… [name of son] *got speech therapy last year, it was a girl came here most of the time. If there had been a place there she would have used it and she felt like that there was an awful lot she could have brought but I think she got that, one hour a week… it's a case of the money isn't there but there is a lot of money there, it's not always well spent…"*

For some, care needs did not seem to have changed over they years (10%; n=3), while for others, provision became more challenging (10%; n=3).

"The financial help actually gets worse, there's the DLA, and we got a Carer's Allowance, but now they've seen our pension, it's taken off us."

"…school to Centre… We had to organise that ourselves... We knew that by the time she got to 18 she was going to have to go. You know, so we looked at what there was… There aren't many options apart from the Centre for [name of daughter]*… There wouldn't be any sort of a work placement."*

"It has stayed pretty much the same... in fact when I was over in [name], [name of daughter] *had just had the stroke and we were in despair, I phoned Social Services here, you know how the Social Worker keeps changing, I never know who it is, it might be so and so, they keep changing round, but there was someone called* [name of social worker], *this was oh, 12 years ago. Anyway, I phoned Social Services. I told them what had happened with* [name of daughter] *and I would be staying over there until she got on her feet... if ever... and would they please look in here and check and see how things were, for* [name of husband] *was here and* [name of son[1]] *my second youngest. He was doing his A-levels and* [name of husband] *was coming back and forwards every week to see what was going on and so I wrote and asked them to call with* [name of son[1]] *to keep an eye on things and do you know what happened? Time passed and eventually* [name of daughter] *and I got home, and about a week after, a letter arrived from the Social Worker... and I didn't even answer it, I was so ripping after all that they didn't even try."*

One mother illustrated the vulnerability of her son and the potential for undisclosed abuse when sons or daughters are away from home.

> *"*[name of son]*'s needs changed at a particular time, at the summer camp where carers and volunteers take them away* [name of son] *was hurt.* [name of son] *came home after this holiday... he was away about four or five days and the young fella on the bus said 'I don't think* [name of son] *enjoyed his holiday'. He was bruised all down when I took off his shirt…. He had cuts... what happened, he had fallen out of the wheelchair and his leg was also hurt... we phoned* [name of day centre] *and our GP phoned, but we couldn't find out…"*

A few of the carers discussed necessary changes with social services (66%; n=19) and got help.

> *"The social worker said* [name of son] *should get it and organised it for me."*

> *"The respite arrangements. … we weren't happy with them, they aren't really suitable, or the staffing for that matter"*

Others were not getting any help with service changes (26%; n=8) or had to fight to get help (10%; n=3).

> *"We would want the Home to Home like the time we went to* [name of country] *for a fortnight, but it's the way they organise things."*

"I had to take her case to court, because [name of daughter] *got no mobility allowance…"*

"We took control of the thing when we made the decision that we were going to have [name of son] *living independently. We made the decision to run this ourselves and we created our circle of support. Decisions were made and the Trust became partners… That's the way forward!"*

As time moved on, informal support systems changed, either because the needs of the individual with disabilities changed, or because the circumstance of the carer changed (48%; n=14).

"Yes, when [name of daughter] *was younger family and friends where able to care for her for short periods of time with some difficulty. However, as she has got older, family and friends are no longer able to manage her."*

"There was a neighbour woman who would have taken [name of son] *for a walk. She was saying 'I remember when I would walk with* [name of daughter] *and she would cry'.* [name of daughter] *wasn't really talking then and she cried a lot of the time. It's a very lonely existence for someone with dysphasia or aphasia or whatever it's called and you can't make yourself understood."*

"Certainly now [name of two siblings] *would be more willing to help. They are older too and he's more settled… The truth of the matter is, the*

family would be much more supportive now. We coped with him ourselves, I coped with nanny's help, with [name]*'s help. She left when he was 14 or 15, something like that… We didn't seek outside help. It was only when I was about 55 that desperation set in. The worry about the future… when everyone else was gone… then I'm left wondering, if I die, then what happens to him…"*

"Well, he needs a lot of … He's getting more independent, but what way will we say it now, his needs for going to places, to youth clubs and going out. There's more work that way. For his personal care there's things, well, but he maturing slowly, developing slowly but getting more independent."

"The level of care that I can give is really nil… I can do less because of my own health problems, but I can still change a nappy, but I honestly couldn't dress her in the mornings." [mother]. *"Because of that, I'd say my share has gone up, but I can't change a nappy. It's a matter of* [name of daughter[1]]*'s dignity really, and we can't ask* [name of daughter[2]] *either to change* [name of daughter[1]]*'s nappy, not because she isn't willing to help, but she has learning disabilities and she would be a bit clumsy, you know it wouldn't be done right."* [father].

"My dad used to live with us. Now my dad was 85 yesterday, and he lives up here opposite [name] *Hospital in sheltered housing… My daddy lived with us, and he would still help out, now we're going out one night,*

maybe for a wee run, we don't go that often. We used to go out separately [name of husband] *would go golfing and I'd go bowling, but if we wanted to go out for a meal once a month maybe he'd come over for 2 or 3 hours…"*

"Well, it was easier when he was small... I had the tail end of my family who could sit, but with sitters when they would get to be about 14or 15 and you could go out for a couple of hours and if there was a particular problem they always had a contact number. But when they came to about 17, they moved on and started going out themselves, so we ran out of that level… then our great nieces, you had that group for a while."

"Well you see when [name of son] *was younger, we lived round there.* [name of son] *was just taken as* [name of son]*, you know it was accepted and you could set him out in the garden along with the other youngsters in the street whereas now you couldn't leave* [name of son] *sitting in the garden."*

The support systems did not change much for a number of the participants, either because they were non-existing in the first place, or because they were well established and supportive all along (38%; n=11).

"No. I never had any help, well apart from my sister… and my mother was very good, but she's dead years… [name of son] *is nearly 47, you know now… I think for most people the support they get is from their own families."*

"Possibly my sister would have… in earlier days but because of [name of daughter]*'s difficulties she was quite apprehensive about it, you know. It's ended up over the years not doing anything. No doubt, if I was in a hole they would try and help but... respite was the only help we could get, you know… and glad of it."*

"Well, the family have always tended to shy away from [name of son]*. It's that 'hidden away' thing. I would say compared to my family,* [name of wife]*'s family were very good. With* [name of daughter]*, we wouldn't get informal help. It's strictly hospice nursing for her respite, I think people would be afraid."*

"They would always have been willing to watch [name of son] *when I wanted them too, and they would have gladly. Brothers and sisters and their families and my own children would have watched him, no bother but I didn't… If I would have been getting the family to watch him, it would have been for a few hours, if we were going out at night or for a day… But when it came to overnight I would have used respite because* [name of son]*'s behaviour when he was younger would have been atrocious… absolutely. From the day and hour he started walking until he was in his teens he was horrendous to work with. The families wouldn't have kept him in a routine. They'd have spoiled him and when you picked him up you'd have been set back about 2 years! So, that was my main reason, not that they wouldn't have kept him but he needed the*

routine and he needed to be kept in the routine. He was crazy, he's a big gentle giant now but then he wouldn't have gone round you. There were days when I had two or three windows missing in the house… My neighbours were a great help, and my mother and father, but of course they're dead now too… They'd have held onto him for a couple of hours while we got sorted out… Our neighbour was a joiner and it got that when he heard glass breaking, [name of husband] *would have been at work…, if* [name of neighbour] *heard glass breaking, he just brought hammer and nails with him, because he knew I was looking something boarded up. So, they were really good… The man at the back had that big garden and he gave him the freedom of it. He had only grass in it, you know, and it gave him great freedom because he couldn't have gone out the front."*

"Well you see, [name of daughter] *was away… we didn't need it, then she was with me and I'm very capable… Is that awful to say? It's self praise which is half scandal! When I had to go into hospital, which was a long time ago, she was in care for that… she was in respite care. It was two years ago when I got word I had to go in to hospital, so I phoned around and phoned the hospital. There wasn't one place that could take her, neither* [name] *nor* [name]*, so my sister had to take her for the month."*

For the most part, carers coped with changes by 'just getting on with it', but as sons and daughters become older, new challenges occur.

"Coping with [name of daughter] *as she and I mature is becoming more difficult…* [name of daughter] *is now more difficult to occupy. I find it difficult to find things that she likes to do and are age appropriate.* [name of daughter] *likes to go on swings and slides in the play park but the parents of other children do not always approve of having an adult play along side their children. When* [name of daughter] *was younger the general public where more understanding and sympathetic if she pushed past someone but this is no longer the case. I am also finding it more difficult to 'keep up' with* [name of daughter]*… not as fit as I used to be."*

"I enjoy looking after [name of son] *but it is becoming more difficult as I get older. I am not as fit as I used to be and I don't have as much energy to look after* [name of son]*."*

"I sometimes think that I am not as tolerant and energetic as I used to be. [name of daughter] *can be quite slow sometimes and I occasionally find myself becoming impatient with her."*

"I've found it more difficult… she has become more cantankerous and she is physically not as able so I have to do more."

"It's not deteriorating, but it takes it out of you. I know we're older, and worry a bit, but we're more experienced too. It's the other things that go to the wall, no holidays, no shopping days. We can never go out together. We eat our meals when the hospice nurse is here."

"And with all this, [name of wife] *has had to attend for appointments with doctors and nurses. We've to fit in our own appointments that fits in with* [name of daughter] *when she's at the centre. She's there for 3 days a week, she's entitled to 5 days but she gets tired."*

"I think well, slowing down would be the biggest problem… Well, suppose I cope as well as I can, you know. I had a fall early in the year and I cracked a bone here in my wrist you know… I found it very awkward at that time, for everything was an effort, you know. It brought me the realisation that I could have done serious damage and [name of son] *would have to be taken into care."*

"[name of daughter] *has a lot of friends and activities. My own support… well the primary care here is so poor. It's a major task just to get any help with my own health problems. I have an idiosyncratic doctor! A further thing from the Independent Living Found… the social worker has implied that there is a 'final sanction', that I'm not a fit person to look after* [name of daughter]*. I've had so much ill health… I'm not really in a position to judge… The worst is being deaf, I really am very deaf…"*

"Uh huh, we've been very independent and I'm finding it now, maybe we shouldn't have been, we should have had more of a network."

"So far so good! I suppose we keep ourselves relatively fit. As I say, I've been a fitness instructor now for umpteen years. I started going to it when [name of son] *was 4 years old and that's the class I take now, step aerobics…"*

"I don't find it very difficult because I don't deal with the detail… I'm quite prepared to look after [name of son] *any time and we get on extremely well and I don't have any great ambition any more to go and do anything… I don't feel the strain on me at all…"*

"Well do you know, that he is lifting things for me this last while now and once again I'm lucky, but I've put on weight and stooping is not so easy, so I'm calling '[name of son]*,* [name of son]'*… but that is going to change, of course that is going to change…"*

"I suppose if someone came in and took a look and said well [name of daughter]*'s mother's not looking after* [name of daughter] *well enough, I don't know that they could say that, but maybe they would see something I'm not doing that I should be doing for her but I don't know…"*

"It's not deteriorating... but it takes it out of you. I know we're older, and worry a bit, but we're more experienced too. It's the other things that go to the wall… no holidays, no shopping days... We're planning a holiday this year... I'm in a Silver band, they're going to [name of country]*, and*

we're all going. It's our first holiday in years, but that's a one-off event... all of us."

- **Carers' physical health**

For the most part, carers described their own health as good or fair (76%; n=22), despite the fact that they were suffering from various health problems.

"I suppose for my age it's very good, but I do have arthritis."

"It's ok, it's ok. It's quite tiring and stressful at times."

"I'd say fair. I have problems with my leg… since before [name of daughter]*, really."*

"Excellent, thank God! We would take him hill walking in [name] *every second Sunday and we go to dancing classes in between as well and my husband takes him cycling. Obviously at our age we're not going to take him to discos and we don't drink so we can't go and sit in bars sort of thing… we're not interested in that."*

"Quite good, I'm on lots of tablets but only normal ones you know, for my age, but that could all change, I was threatened with diabetes but it's not there that was a couple of years ago… you couldn't be perfect at 75…"

A number of participants stated that they suffered ill health.

"I can't say what it is... Something in my head, I have to use a stick. I don't use it around the house, if I go out. I can still drive which I'm very happy about."

"I have heart problems as I said, and I'm diabetic too."

"I have coronary heart disease if you want to put that down… after having peripheral arterial problems with my legs."

- **Carers' psychological health**

The average GHQ-12 score for 26 participants was 3.61 (data missing for 3 participants); 35% of the participants scored over 4, the threshold at which Goldberg et al. (1996) recommend further psychological assessment. A recent large-scale study in the same locality resulted in 17% of the general population scoring over the threshold of 4 (ARK, 2006). As such, participants in this study were more than twice as likely to experience psychological ill-health than the general population.

- **Family relationships**

For the most part, participants explained that they had very good family relationships. Those who still had their partner generally were happy with their spousal relationships.

"We get along fine, spent so much time over the years caring for [name of son] *that we never had time to have an argument."*

"He's a civil creature."

"I suppose, it's a good working relationship."

"…love goes out the window when you get to this age! Ach well, we struggle on."

"[name]*, my husband… och, excellent. He's very easy going, God love him… you know what pressure you're under. When* [name of husband] *was working I'd have been a 24-hour carer except at weekends but I never… whatever happened with* [name of son] *during the day was over, I never said… he would say how did things go and I'd say 'Oh grand', though he might have seen there was two windows boarded up… So he knew everything wasn't grand but there was no point me saying 'Oh wait 'til I tell you the day I had today. I done this and he done that' and I hadn't the energy to go over it again anyway. Anyway, he never really showed that bad behaviour to his daddy. So by the time I twigged this on, he had me wrapped round his wee finger. There was no point in complaining to* [name of husband]*, because he was already well-behaved… I was the problem and I had to teach him to behave when I'm there. I would have given* [name of husband] *an outline after* [name of son] *went to bed but I would never have got* [name of husband] *to say anything to him because the issue wasn't his behaviour with* [name of husband]*, it was his behaviour when I'm with him…"*

"God Almighty, we were friends for 9 years… reliable, reliable, he just does not change… I'm not joking now, nobody when we first got married thought '[nickname]*', as he was called then, would accept the situation* [with son] *but that has never been the case…"*

Participants generally described their relationship with their son or daughter with disabilities as very good.

"A great lad, love him to bits."

"Ach, well goodness me, I've a good… well I love him. It's a loving relationship and he can communicate with me without words, I usually know what he's saying without him saying anything, you know?"

"Oh, he's my best friend now I suppose, well that's not… I can't discuss things with him but he is my… he is just… well he's the one person in my life at the moment, the important person. Which is why I'll have to be very unselfish, when hopefully the Social worker does find a suitable place, even for a trial period, to let him go."

"How would I describe it… is he a pain [*laughing*]*? To me he's a joy and a pain all wrapped in to one… I look at him and think he's marvellous. I admire him, for where he is, how he is, and what he's done, and obviously, there's unconditional love… I don't feel him a burden any more, I would have…"*

"That's not the word she uses. She said she felt privileged to be associated with him…"

"Well I would say good, very good, if she threw a tantrum or anything then I would maybe speak but she would come along later and say 'Sorry Granny, I was naughty' or something. She's very affectionate. She does things for me. She takes [name]*'s water up for her at night, puts on* [name]*'s electric blanket, and closes the window, things like that."*

"Very good! He's very, very pleasant [name of son]*, you know? A lot of mothers say that children with Downs' Syndrome are very pleasant you know, it's just their wee nature. I suppose they get frustrated too, that's why I like* [name of son] *to have loads of activities and that, because some people have asked me in the past 'Would you ever say?'… and wee* [*name of granddaughter*] *would say '*[name of son] *has Downs' Syndrome'. I never would say to him unless he asked me the actual question, because I'd be afraid that he'd be feeling different from..."*

Only one mother mentioned poor quality of relationship.

"My relationship with [name of son] *is not that great. We rub each other up the wrong way."*

- **Provision for sudden or long-term illness of carer**

Arrangements in case the main carer fell ill varied. Most participants stated that they would rely on family carers, i.e., siblings of sons/daughters with

disabilities (24%; n=7), spouses (28%; n=8), sisters/in-laws (14%; n=4), or their own parents (n=1).

"My other children or family… this has happened in the past but only for a few days. If I was sick for a prolonged period, I do not know what we would do."

"If I am ill my other children help out. This has happened on several occasions but they have their own children to care for."

"My husband. In the past this has resulted in him needing to take time off work."

"[name of husband] *has always been a big part of her care, a very hands-on father. You hear about these other men who don't but* [name of husband] *has always been more than good with her. Other people have said this to me, 'Isn't* [name of husband] *great with* [name of daughter]'. *Ill? It never happened.* [name of husband]*, you've took off work if I was sick. It's never really happened… No, touch wood."*

"I've had to go to hospital a couple of times, it would be two years now because I lost my voice and I had to go in for investigations and [name of husband] *was able to watch him you know… He's about 5 years retired… he's 63."*

"Well, I have a daughter-in-law who lives not far down the road, I was in bed for a couple of weeks there and she came a day."

"[name of son]*'s wife.* [name of son] *lives in* [name of town]*, and his wife she's a pharmacist. She came a day, they all come and brought cooked food and put it in the freezer and that sort of stuff, and came up and made your bed and gave orders."*

"[name of son] *wouldn't have his father caring from him*, *I think... but one of his brothers,* [name of son[1]], *is his favourite person in the whole world, but* [name of son[1]] *is working in* [name of country]*, and he's only home at the weekends. In fact he's only home once a fortnight, and he's married and has three daughters, and he lives down the road about a mile from here and so* [name of son] *loves his weans as if they were his own, if you know what I mean... he hugs them, and loves to see them coming and hates to see them leaving... while I'm glad to see them leaving! So* [name of son] *loves* [name of son[1]]*, and when* [name of son[1]] *comes in his face lights up you know."*

"It was dreadful... I lay out in the hall and I couldn't get up... I think [name of son] *was upstairs or something... eventually I managed to get to my feet and I got a friend… not that day, the next day, I wasn't able to get out of bed the pain was excruciating and she took me to the doctor and I got painkillers and then it was very bad and a week later I had to go down again and got stronger pain killers and I was just trying to manage*

and that's when I was very glad of his helper coming in. He was more than good, for he turned back my bed for me as well as [name of son]*'s you know."*

24% of the participants (n=7) did not have any arrangements at all for the eventuality of the main carer suddenly falling ill.

"Not even reserve foster parents, she'd have to go into a children's ward… we had to go to a wedding, and the children's ward was the only place they had."

"There is no arrangement… we could ask our home help, but she does a lot of others too …"

"God forbid that would happen. I have no idea. Is that an awful thing to say. A sudden emergency? No, I haven't, now you've brought that to mind, that's…"

"No, none. It's very sensitive to approach it really and the odd time you would say something the boys just don't want to hear… 'Leave him alone, he'll be grand'… I went through a stage about four or five years ago… 'What would happen to [name of son]*?'; 'Don't you worry about him'; and 'I need to make a will' and* [name of son[1]] *said 'as far as that's concerned don't you worry about* [name of son]*,* [name of son] *will be grand', but I feel it's awful. They might be landed with a situation… see he's away all the time. Say you were to make a will, when you're well*

you don't think, [name of son] *is not capable of looking after anything on that level but I cannot bring myself to say where everything was… always in threes, and I can't bring myself to leave him out but including him… I can't see them managing on it because the boys would be looking after him and I wouldn't want them financially disadvantaged… and* [name] *is 83… but he would know the boys would look after* [name of son]… [name of son[1]] *is the kid who nearly reared him. I think, we should do it some of these days. Things can change very quickly… It worries me terribly, but the fact that he has two brothers is a great bonus for him… but to be realistic* [name of son[2]] *has two wee fellas of his own… but it's going to have to be their choice, but he wasn't very welcoming to the grandchildren… He loves them now…"*

The issue was particularly complicated for one of the carers, who was in the process of separation from her husband.

"Becoming ill has never happened yet, this is it, you see. Well, at the minute it's probably going to happen because men don't like parting… I'm in the process of separating from [name of husband] *and he doesn't give any maintenance…"*

Substitute care arrangements that were in place, were agreed informally and social services oftentimes were not aware of these arrangements (48%; n=14).

"*This is something that my family have done… there have been no meetings about it."*

"Not sure if care plan exists… agreement between family."

"Unspoken."

"Yes, I think she would, in fact she said to me recently she'd like to live in a house of her own. I would die if she left!"

"Don't have a care plan. Family just respond to situations as they present."

However, most participants did not have specific plans in case of sudden illness and even those who had been trying to make arrangements were unable to do so (48%; n=14). The complexities of making plans for short-term illness were apparent.

"There isn't anything, is there? We were looking for extra residential care."

"It's an older population of people with learning difficulties, and they're not prepared…It used to be that maybe a person with Down Syndrome didn't live much past 30 or 40, but it's changed a lot…"

"The only thing that is there is this… it's not... it's vague… that [name of daughter[1]] *will take care of* [name of son] *if anything was to happen. She's got the room and that, up there, but initially,* [name of daughter[2]]

would have been saying 'That's not fair' and I'd have said 'Hey, they're family and the family will take responsibility when we're not there'. I'm softening up on that now you realise they have their own family…"

"Well as I said I did, last year I asked the social worker to call especially to see me about that but he hasn't come back since."

"…my husband has pursued certain avenues with regard to getting a residential facility locally. He could talk to you about it for an hour I'm sure… He's gone to the lengths of… We had someone who was prepared to buy such a place near, I'll not go into the detail on that, and provide the services but it was turned down so he's gone to an ombudsman to look into that. Ideally we thought if we had somewhere in town, that [name of daughter]*'s used to, and that her family and friends and that could pop in and see her, and we could see her in that before we get to that stage of not being able to… but such a place doesn't exist."*

"Well I've only brothers and no sister but I've got a sister-in-law, in fact, two sisters-in law I'd be close to, but they have been ill... those main ladies in our life, we wouldn't ask them."

"Well we always talk about it and she'd like to see [name of daughter] *settled someplace maybe before I die… I don't want to sound… to say that I want to keep her here or be selfish. I wouldn't want that but I don't*

know if she's ready for a home. I don't know how to explain to you how I feel about it. She's so content here, just knows her way around, and everything… this is her home. The thing about independent living, if someone were to come in, it wouldn't be my home then any more… unless you could section an area off which you can't really do. So, I don't really know what the future holds… but I think it's a big problem, not only for [name of daughter] *but for many* [name of daughter]*s out there…"*

"Well, his father would, because we have good enough relations… I probably would… some of the family would have to look after [name of son]*.* [name of son] *cannot be neglected in any one way or another… because he's almost 14 and he's doing well and I don't want that put into reverse because his wee limits. They have limited abilities where other people have all the chances in life, they have limited abilities and I want to give him as much as I can…"*

For others, friends agreed to help out in case of sudden, short-term illness, although these agreements were informal.

"Understanding that someone will be there if needed… no formal plan."

"They understand that some of them will help out."

"Look at the shape of us! We do think what about the future…"

- **Futures planning**

The vast majority of participants had not made long-term plans for the future care of their sons or daughters with disabilities (72%; n=21).

"Haven't made any arrangements as yet."

"Don't want to think about it."

"Not given this consideration, hope to outlive her."

"Don't really know the options."

"Not really, no, we haven't… we're just hoping to remain healthy."

"Not at all, I know I should and I know we should be thinking about it… Any one of the two youngsters would take him, any one of his two siblings would take him but I have a thing about that, taking him full-time… They have families of their own but apart from that, from they were born they have already shared that life with him and it wasn't easy when they were youngsters you know, you couldn't take [name of son] *every place. They were curtailed and they never ever complained. I would say 'You can't go to* [name] *because there's too much noise in it for* [name of son]' *and it was only when he went into respite that they had that couple of weeks that you could take them wherever they wanted to go. So their life was pretty much curtailed right through their*

childhood and right up until they were married, they shared their life with [name of son]. *So I think it's a terrible burden to ask them now to go back and even ask their youngsters to share it. I know he's easy… but it's still 24-hour care and their lives will be changed. They can put their youngsters in the car and go wherever they want and do what they want to do, and if they're looking after* [name of son] *they can't do that. They'll have to arrange to take* [name of son] *with them and as they get older, and even when they're young,* [name of son]*'s just going to be an old handicapped uncle… We can't do it because of him and I couldn't blame the youngsters…"*

"There are no plans for [name of daughter] *at all. She is our foster-child, so what can we do? It really takes two people full-time to look after her. We're worried she will end up in some institution, it was mentioned in her last review. 'She would be well looked after', but they never produced any plans. Ideally, there should be standby foster carers…"*

"Well, not… I did say one time that [name]*, you know, that eventually I'd like her there, when I say there, I mean* [name of daughter] *needs stimulation, she's active and in some settings, they become… quite different…"*

Only few who had made plans were clear about what would happen to their son or daughter when they were no longer able to provide care.

"My youngest daughter will care for [name of daughter]*."*

"Probably look at supported living, he'll be able to live with support."

"We have set up a property trust to protect the property. [name of son] *wouldn't be able to manage it on his own. There are five Trustees… three of them are our best friends… if anything were to happen to us. There was no care plan offered to us."*

"Well, I had thought when I first heard of [name] *and read his books that I would have liked* [name of son] *to have gone into one of those homes but again they are few and far between and I know one home was opened in Belfast, if I say five years ago, and I have kept in touch there but when it was opened they did point out to me that they had so many of their own…"*

"There are several options, the [name] *Village and* [name] *House, the* [name] *home in* [name of town]*… I helped set that up and* [name of daughter] *prefers that. She has a friend there and she goes there for Friday lunch, and stays at her friend's flat for the evening. Another option is to turn this place into a home, with* [name of homehelp] *looking after it all."*

"Well, I would hope some of the girls, you know… would… well, I mean… I have my house sorted out in case of accident because I'm 60 this year and I have my house that if any… God forbid anything did

happen to me, I've it sorted out that [name of daughter[1]] *would take the house and look after* [name of son]*… I have done that, I was coming into my own house instead, the solicitor… well you have to think of* [name of son]*, that could be changed but that's the plan in case anything did happen to me you know…"*

"…well if anything happened to me it would be their decision, I left it that [name of daughter[1]] *could sell this house because I think in the olden times it was different but now, we'll say that if they take up what I wanted them to do, it wouldn't be fair to make her live here. If she gets the house or whatever, she can sell it and take* [name of son] *wherever she wants to…"*

Most participants had not discussed future provision with social services (66%; n=19) while those who did found advice helpful.

"Have not had any discussion regarding this or been offered any advice to date."

"No… have not discussed future options with anyone outside family."

"No, except they take him in for respite… although I would be very aware of the services available because from [name of son] *was very young I'd have got myself involved in meetings with the Health Trusts… 'planning for the future' so we would be involved in that, I would represent the* [name of town] *parents and they invite us along to all those meetings…"*

"No, I don't see them or know anything about them. Well, I needn't say I don't know anything about them, I know they are there but someone said it's pretty hard even to get your social worker, so I haven't bothered. Things have just been going on for years, when we had the mobile home, we'd just take off, when I was more able…"

"Social worker? Oh yes, in fact I was chatting to her on Monday… I'd gone up to [name] *with some wee presents we'd brought back for the ladies there and she was there. She was just back from having a baby and she said she was meaning to come out and see us, but I said no, you're grand, the only thing we were chatting about is the problem we have with* [name of daughter]*… with our wee grandson. And she said she'd come out. She's very, very nice but as I say she's been off for a while, we had a replacement, she was out with us a couple of times, an English girl, but she's moved on too."*

Participants generally did not discuss futures planning with their son or daughter with disabilities.

"Don't need to trouble him with that talk."

"Well, I haven't even… she's said 'I would love to have somewhere but don't worry Mammy, I wouldn't go'. I would miss her terribly... she is really supporting me."

"…and you can destroy a disabled person's life with money… if they have any money, then they will lose their services. We've mentioned to the girls about being executors but they started to cry and we've never mentioned it since…"

"If we had someone who could talk to us! Give us some advice…"

"I can say right away that I have never said to him… but I have heard him saying what would happen if mother went and he had this look of panic on his face."

"Well I haven't, she'd say you're not going to die, you know? I'll not say it would upset her but she might be dwelling on it or thinking a lot about it?"

"No, my goodness, [name of son] *is …* [name of son] *is very limited... I was told once… my husband and I took him, he was 17, thirty years ago... to* [name of town], *to a very good order of nuns, a French order and they had a home we had thought at that time it sounded ideal for* [name of son] *and we went along and paid for… the educational psychologist and we left* [name of son] *with him for most of the day and he gave us a full report and he said that* [name of son] *understood you know... his speech… he understood all spoken language, he could follow directions and that, I could send him upstairs and say* [name of son] *would you get me… provided … you don't give him two or three things to*

do. He recommended... at that time the nuns weren't keeping boys past 16 years and he recommended a very good place in… my head, I've forgotten… over the years, at the time we were so disappointed... this place was run again... the grounds belonged to an order, it was lay people running it and they had everything within the complex... school, shop, playing field, Post Office. I don't know if boys were encouraged to go into the little village on the bus but they were trained to use the bus and he thought it would be ideal for [name of son]*, don't forget* [name of son] *was only 17 at the time, and we had high hopes of that but they didn't have ay places... I sought help from a friend who was a senator in* [name] *and he did his best but he told me that they had so many of their own… from that part of the country, that the teachers just couldn't take anybody from* [name]*, so that was that. I have tried... not to get rid of* [name of son]*, but to do what I thought would have been good for* [name of son].

Some of the participants had made arrangements to ensure future financial security for their son or daughter with disabilities (28%; n=8).

"We just made a will last year and our oldest daughter said that she would… look after her."

"Yes, we've a trust set up for her."

However, most had not considered making financial arrangements for the future (72%; n=21).

"As I said, we haven't talked about things in any great depth."

"Not at all, I know I should and I know we should be thinking about it…"

"No, except the daughter but I haven't got around to doing that…"

The importance of futures planning was apparent to most participants and they generally thought that plans should be made as early as possible.

"Probably should have already made plan. Now would be a good time!"

"Probably long ago … it's another thing that's worrying me…"

"As soon as possible, because… when you're young you think things will never change. Your health can change in the blink of an eye."

"We really should have it started, personally speaking. You know we keep saying we should do something, we should do something but it seems awful to have to face it… You think, oh God maybe if you ignore it something will just happen and it will all get taken care of… which is a wild thing to do to hide your head in the sand… You work so hard all your life to get him to where he is, to get him to stay at home so why are you stopping now, why can't you face this like all the rest of the problems, you faced them and you got over them and you dealt with

them …but [name of husband] *and myself keep saying 'something will turn up'."*

"Oh now, yesterday… you can only plan five years in advance I think."

"Five years ago!"

"I would consider my case slightly different. [name of daughter] *has always been so capable over these last number of years. Whenever I go into a meeting or building with a group of these children with learning difficulties, I say to myself 'Well, you haven't a handicapped child at all', and I don't mean to be boastful, I'm just thankful but that's how I see it. Therefore I wouldn't be the very best person to answer that question, but if I were a mother of a very troubled child, I could probably answer it very well for you… It all depends on experience and whatever the disabilities… I don't know, if I ever said 'Why me' but I can tell you with maturity you will say 'Why not me?' Forty years ago my sister was at a mission and the speaker spent the whole evening talking about these children, handicapped children as they were called at the time, and he said whether you like to believe it or not they are only sent to special homes where they can be provided for, they're not sent to every home. I suppose it was a turning point for me…"*

- **Advice to others**

Participants offered a range of advice to parents of young children with disabilities.

"Be prepared for a lot of hard work but great company!"

"Do not always depend on social services… they often let you down. Look at all the options available and request that social worker provides more than one option."

"Find out what is available in the local area."

"Plan for it early, introduce child to other carers, e.g., respite, early."

"Probably give some consideration to this issue earlier. Look at what options are available and discuss the future with your son/daughter as they grow up, just like you do with other children."

"Don't move back to Ireland from [name of country] *in the middle of it."*

"Just take life as it comes, don't get too annoyed and things will work out."

"Keep at social services if you want to get anything."

"Start as early as possible, have it in your mind what it is you are looking for."

"Try and make them as independent as possible… to learn their child to be independent."

"It's so hard to know where to go... where would you get a straight answer? Everyone is going on the Internet, but I'm not sure that's a good idea."

"I think sometimes it can be confusing. You can have too much information. I wouldn't know where to go for advice. I'd be saying 'I know this child better than you'. I know we're all going to die, but you get a fleeting thought…"

"As I said, investigate the facilities, inspect them… one of the other options was a home in [name of town]*, which is for blind people… but* [name of daughter]*'s perceptions change too, and you also need to be careful how things are left so that benefits aren't lost."*

"Take control. Yes, accept the fact the buck stops with you no matter how well meaning the social services. It's still your child… no matter how good. It's all about care; who's going to replace the carer and the best bet is family and friends… You have to identify those people and set it up and trust your judgement rather than a residential home… You have

to make your own network, and the natural one is the family and friends, the system you have, to take responsibility."

"At the end of he day, if they don't have a caring family or better still loyal friends… it doesn't matter about age, colour, class, creed, denomination… An absolute network, yes… they used to say about these caring orders, they had a continuity of people, nuns had a vocation and they were always there. A continuation of care not that but a continuity of friendship…"

"Of course as you're going along and I had the opportunity of doing that as [name of son] *was the youngest, even putting a bit more effort to making him… I like to give* [name of son] *every opportunity because I'm with him and can give him more time to make him more able when he'd grow up… as independent as possible, that's why I really like him going to youth clubs and going to all these things… any opportunity that's going. I try to make him you know, take it… and used to other people."*

"I wouldn't advise someone else, because I think it depends on your own individual… how severe your child is and how it affects the rest of your family and everything else. I'm quite happy at the moment because [name of daughter[1]]*'s here, I'm speaking for myself, not* [name of wife]. *Should something happen to us* [name of daughter[1]] *will be and has been told… she expects to take* [name of son] *up with her. She's been told... if that doesn't work out you're going to have to find something*

else, I'm quite prepared to let [name of daughter[1]] *decide when that should happen. That's just… I realise we all have to go sometime… we can't carry on the way we were doing before but as long as we can do it, we will do it."*

- **Retrospective**

A number of issues were mentioned when participants considered what they wish they had known during the process of bringing up a child with disabilities.

"Would have liked to known what alternatives there where to day care and also would have liked more gradual transition for [name of daughter] *from school to day care."*

"Wish I had requested additional support and services when boys where younger, e.g., speech and language."

"Think it would have been useful to introduce [name of daughter] *to other services, such as respite earlier so as she is not so dependent upon me."*

"Wish I known more about job support scheme, could have been better prepared, monitor progress more closely that level of support needed is delivered."

"Goodness me… if the child can't communicate… you would really need to plan it around what the child wants. The child would need to be

compatible with the person that's caring for them… no point in setting up something where they aren't compatible with the person that's being cared for. I'd say that would be the first thing."

"The special toilet we have now… it's like a bidet, it washes and dries you. [name of son]*'s muscle tone isn't good for cleaning himself and I used to get up six or seven times in the night."*

"We don't have a lot of confidence in general with the sort of professionals who have a lot of 'book knowledge'. There was a teacher at [name of daughter]*'s school... she was there a long time, teaching the deaf-blind and when she retired she said she wanted to have a child around the house so she adopted a deaf-blind child."*

"When you have a handicapped child first, you… unless you have a family where you realise there is a strong possibility that every child will be like this, I don't see how it should change you… people have smaller families now anyway… the bottom line is, it's still a child…"

"Well, ideally if they can get family to say they were prepared to do it, that's something… I've got a friend and she knows that her daughter is going to take her other daughter and that's it cut and dried, and she's so lucky… and I'm not saying that mine don't care, don't get me wrong, it's just that at the moment they're pursuing their own professional lives so

you know… and they have their families, and they have a husband there…"

"I certainly wouldn't have gone in for the ILF thing. It's been a disaster for me, though not altogether for [name of daughter]*, as she likes the carers. I think the fact that you have a caring temperament… you have that responsibility. The worst challenge is the primary care, the lack of education among GPs and the Community Nurses."*

"I suppose at that stage you're pretty young, if you're working, you could maybe think of something financial or that. Immediately… for a teenager, you'd be looking at their day care facilities, what their capabilities are and you should look at what their likes would be, plan the care around the person themselves, what they call now person-centred planning. Find out what they can do and what they would like and run with that rather than just automatically feed them into a day centre. Can they work out for a couple of hours someplace even an hour a week, a half-day, doing something meaningful? Years ago they were just automatically slotted into day centres whereas now especially when they have a capability for… they're going to be going on, they need something worthwhile. There are some ones even with a learning difficulty who want to live on their own in sheltered accommodation; it should be a choice for them... If they don't have that higher ability then they haven't that choice, they have to stay at home if the parents can… some of the parents don't have the health and they can't offer them that choice, so

are they looking at a hospital situation. Most of them at school can manage even with a severe behaviour problem, but once they're 19, they leave school then… it's a long day… you have to take measures then. That's when I noticed [name] *House, when school years are over it's then they go into full-time care. You'd have to be planning that well in advance and where's available."*

"[name of son] *was born in 1970s and* [name of condition] *was only named… We read up a bit and knew what we were getting into…* [name of son] *was in hospital for about six months and they thought he wouldn't survive but we took him home and we wondered if we should join a society… but the paediatrician told us 'Take your child home and you believe that your child has the same potential as your other children' and we didn't join any society until the differences started to appear. I think that did wonders for raising* [name of son]*… I tell the parents I' m working with now, don't limit them in any way… obviously they need to know about speech therapy and educational opportunities but not what the caring will be like, what will it be like being accepted by society, finding jobs… treat them like any other child and enjoy as much as you can."*

"I'm sure with more knowledge… maybe I should feel guilty, I'm sure I could have done more but I've come to terms with it, with all the emphasis on education I don't think [name of son] *would have done anything more than he has."*

"I don't think I'd have done anything differently because no matter how you plan something, something may turn out differently anyway. You just deal with everything on a daily basis. They say the alcoholic's prayer is a day at a time. But it's not the alcoholic's prayer, he'd be very selfish to adopt that, it's everybody's prayer. You don't know what the next day brings, you don't know what the next minute brings so deal with things on hourly or daily basis and you cope as well, you plan as well as you can to a degree, but I'm not being naïve as to what would happen if I were to die tonight but I'm sure someone… they wouldn't put [name of daughter] *out anyway either my sister or my niece…"*

Only few carers thought that there was nothing they would have liked to have known earlier (10%; n=3).

"No, we had everything organised in [name of country]*, services are not as well developed here."*

"No, I don't, well when I look back to babyhood, well [name of daughter] *didn't need care until she was 22 and I suppose time has helped there, I don't look back and regret anything, and with* [name of son]*, there was no help available... and I also cared for my mother-in-law who had Alzheimer's and who died when* [name of son] *was about 3 or 4 years old."*

Section 6: Interpretative analysis: 'Making sense'

This section moves from phenomenological descriptions to conceptual and contextual interpretation. Interpretative phenomenological analysis (IPA) is inevitably subjective to the extent that different researchers may not interpret the same phenomenon in the same way. Although this issue is not specific to IPA, intellectual honesty demands that this complexity is explicitly acknowledged.

- **Reflections on researchers**

As with all research, the researchers or scientists cannot be divorced entirely from the research process. They form an integral and reflexive part of the research questions that are asked, the methodology that is used, the data that are collected, and the subsequent analysis.

The current research team comprised experienced collaborators who were knowledgeable and well tuned-in to the issues of carers of individuals with disabilities. The first author, Karola Dillenburger, is a Senior Lecturer in Inclusion and Special Educational Needs at the Graduate School of Education, Queen's University Belfast (QUB), a clinical psychologist and Board Certified Behaviour Analyst, who designed the research question and methodology and was the grant holder. She has wide-ranging experience in conducting quantitative and qualitative research in various areas, including parent training, trauma and bereavement, autism spectrum disorder, and child abuse. She is the mother of four children.

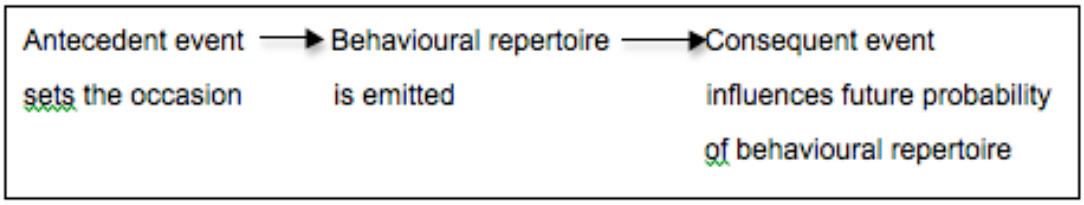
The second author, Lyn McKerr, was employed as a research assistant on the project and conducted most of the interviews. She is an anthropologist and archaeologist with much experience in interviewing older research participants. At the time of this project, she was at the final stage of her PhD research at QUB, She is a mother of five children, her youngest being a 17-year old boy, diagnosed with Asperger's Syndrome. Liam McDermott and Siobhan Owens, both of whom provide assessment and interventions to individuals with a learning disability and ASD in one of the Northern Irish Health and Social Services Trusts, conducted additional interviews in particularly rural areas to which they had access. Both are nurse-trained and have wide ranging experience in working directly with parents of children with disabilities and behaviours that challenge.

- **Theoretical framework**

Gallagher and Keenan (2006) outlined the theoretical framework that was adopted here (see also Cambridge Centre for Behavioral Studies, 2009). They contrasted traditional psychological approaches that commonly relate *age* as the independent variables to *developmental milestones* as dependent variables, with a behaviour analytic perspective in which *environmental events* are identified as independent variables, while *behaviour* (publicly observable, private, verbal, cognitive, and emotional) is regarded as the dependent variable in the analysis. In behaviour analysis, if-then relations between dependent variables and independent variables are called contingencies (Baum, 1994; Michael, 2000; Skinner, 1972; Whaler & Fox, 1981). Figure 1 is a simplified illustration of the most basic behavioural unit of analysis, the

three-term contingency, in which A stands for antecedent events that set the occasion for behaviour (B) to be emitted. The future probability of B depends on consequent events, C. C either leads to an increase in the future probability of B, in which case the term 'reinforcer' is used; or C leads to a decrease in the future probability of B, the term 'punisher' is used.

Figure 1: Illustration of ABC contingency



In lay language, contingencies can be understood as the *circumstances* that influence or *shape* the behaviour of individuals or groups across the lifespan (Dillenburger & Keenan, 2005). In behaviour analysis, explanations for behaviour are derived from a detailed analysis of how contingencies affect behaviour (Hanley, Iwata, & McCord, 2003). Gallagher and Keenan (2000a; 2000b) used the behaviour analytic framework to expand behaviours of older residents of care homes. The scientific perspective of behaviour analysis is used here to provide a theoretical framework for phenomenological findings.

- **Verbal accounts of behaviour**

Behaviour analysts are generally apprehensive when research relies on verbal reports alone (Keenan, 1997). This is a legitimate concern because, of course, the verbal account of an event is not the same as the event itself (Skinner, 1989). In addition, Kenneth Lloyd (1994a; 1994b) identified the problem with correspondence between verbal and non-verbal behaviours

when he showed empirically that what is *said* does not always correspond with what is *done*, i.e., verbal predictions of behaviour do not always correspond with actual future behaviour, and retrospective verbal descriptions do not always correspond with past behaviours. Because of considerations like this, behaviour analysts usually prefer to rely on direct observations and inter-observer agreements for more discernable data.

Despite these reservations, however, verbal reports are an essential aspect of behaviour analytic work. For example, the behavioural interview is an integral part of functional assessment and analysis (O'Neill et al., 1997) and verbal ratings have been used to aide experimental analysis of behaviour (Kelly et al. 2005). Phenomenological accounts are considered important descriptions of contingencies (Hayes & Brownstein, 1987; Leigland, 1992; Wann, 1964) to which participants were exposed and which affect their behaviour and the behaviour of their sons and daughters with disabilities as well as their relationships to each other.

- **Relationships and behavioural networks**

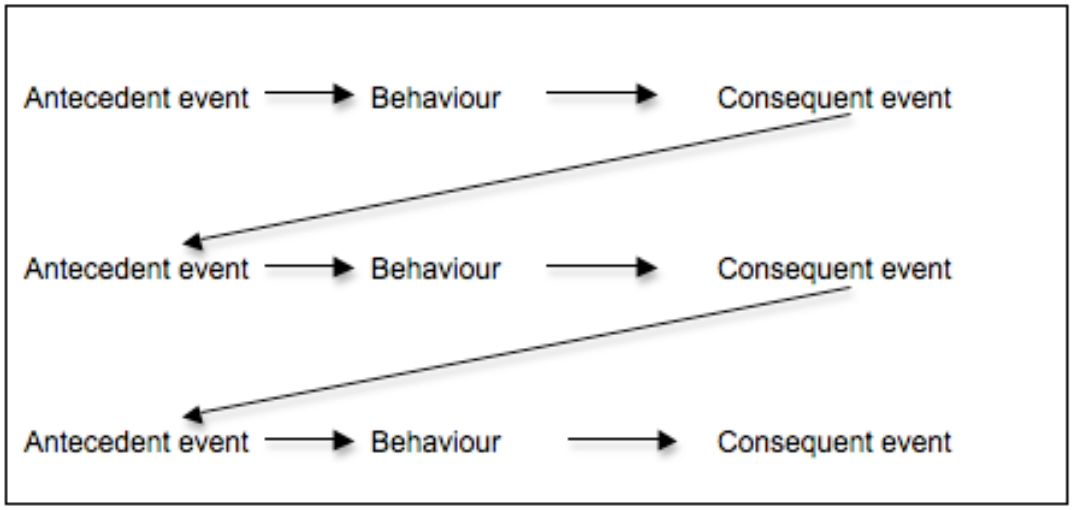
Verbal accounts reported in Section 5 described the complex network of relationships between carers, those for whom they cared, and the outside world. The term *relationship* is commonly used as summary label (Grant & Evans, 1994) for interrelated, intertwined, and/or interdependent behavioural patterns. Like two dancers, the behaviour of individuals in relationships is negotiated and shaped into specific behavioural repertoires. While some behavioural repertoires appear frequently, others are emitted at low rates. In

other words, behaviours can be part of a repertoire even if they only occur once or twice a year, e.g., blowing out candles on a birthday cake.

In many cases, carers described their own behavioural repertoires as just as dependent on those for whom they cared as the latter was on the former. This was the case in particular for emotional and social support after bereavement, for practical support with other disabled siblings, or when carers were unwell. Interestingly, mutual dependency had little to do with actual levels of impairment. In fact, even severely impaired offspring provided support for carer behaviour, although obviously the level of practical help varied.

Figure 2 is a simplified illustration of mutually interdependent repertoires that develop when consequences for one behaviour become antecedents for another.

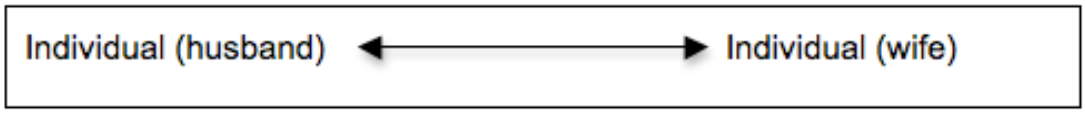
Figure 2: Illustration of mutually dependent behavioural repertoires



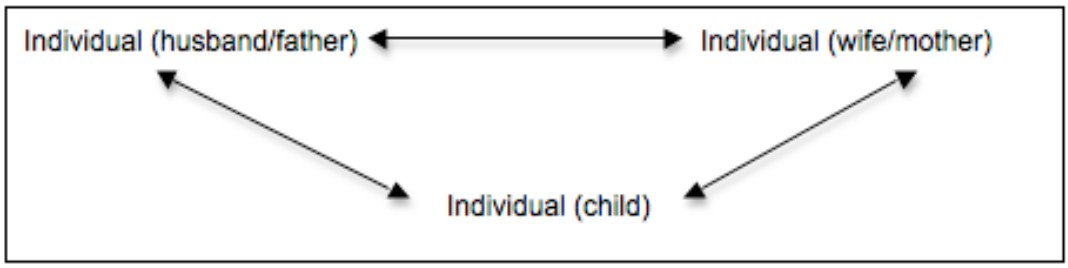
Of course, relationships are not uni-directional and do not develop in a vacuum. Phenomenological accounts (Section 5) showed that relationships between carers and dependents constituted an interwoven network of behavioural repertoires that constantly adapted to circumstances. Figure 3 illustrates the network of multiple relationships within families (adapted from Moynahan, 2001).

Figure 3: Illustration of family relationships

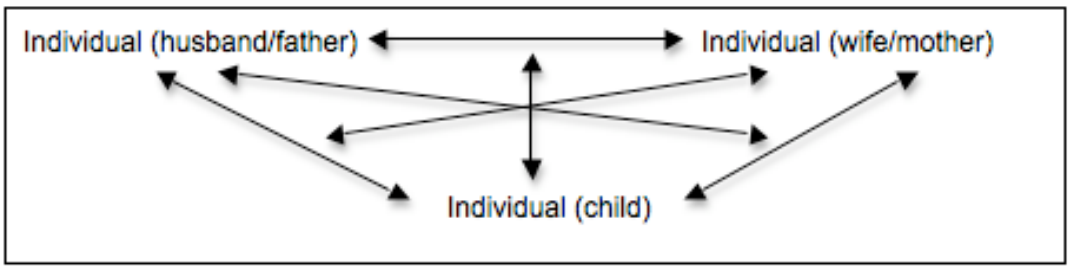
Reciprocal relationships between individual/husband and individual/wife



Reciprocal relationships between father, mother, and child



Network of reciprocal relationships between father, mother, and child

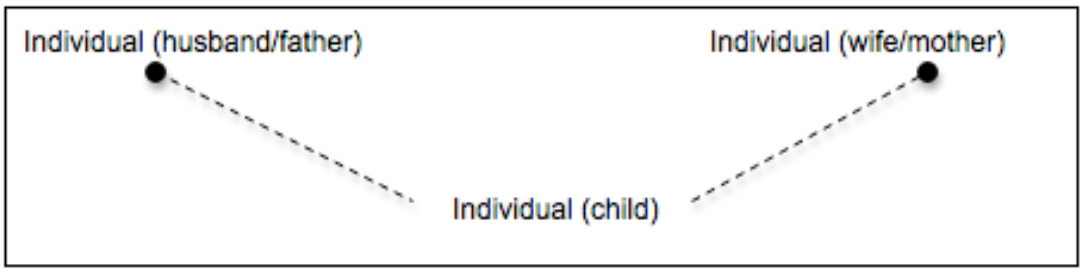


First, the couple dyad develops. Behavioural repertoires of each partner differ and the mutual relationship that develops is complex, unique, and includes a

new range of repertoires, such as being each other's best friend, lover, confidant, advisor, husband, wife, etc. When a child arrives, additional relationships develop in the triad. Importantly, these relationships change over time as the needs of each individual changes; for example, the relationships between mother/father and newborn differ substantially to those of the same mother/father when the baby grows to be a toddler, school child, adolescent, and eventually, adult. The birth of a child does not only add to the complexity of the network of relationships, it also changes the characteristics of previously existing relationships and, of course, these changes are reciprocal. Obviously, where more than one child joins the family unit the complexity of the relationship network increases.

Figure 4 illustrates what happens when both parents have passed away. The offspring usually maintains some kind of uni-directional relationship with the deceased by thinking about them and missing them (Dillenburger & Keenan, 2005), however, if there were no other support network, the individual with disabilities would be on their own and inevitably in a crisis situation.

Figure 4: Illustration of lack of relationships when parents pass away



Fortunately, family relationships commonly do not develop in a vacuum and other social relationships add to the complexity of the network, e.g., through

school, work, or leisure. However, where only minimal social support was available during the lifetime of the parents, there will be a severe lack of support for a child or adult with disabilities once parents are unable to care or have passed away. Confirming earlier studies of widows of the *Troubles* (Dillenburger, 1992; Dillenburger & Keenan, 1994/2001), those with inadequate networks of support described isolation, loneliness, physical and mental health problems, and heightened stress levels.

- **Functions of behaviour**

This report showed that participants were twice as likely to experience psychological ill health and stress than the general population. A functional behavioural analysis identifies causes of stress as either a deficit of skills or an excess of task demands (Dillenburger, 2000). Phenomenological findings reported here indicated that by-and-large carers were highly skilled in dealing with the physical and social needs of their sons and daughters, at times more so than professional care staff. Skills had developed over many years, were flexible, and generally well adapted to evolving circumstances.

Stress therefore was not caused by skills deficit but by tasks becoming too demanding. This was experienced on two levels. First, as carer's own physical strength and health decreased it was becoming increasingly difficult to complete caring tasks, especially if they involved physical lifting or social supervision. Second, ageing sons and daughters themselves developed increasing care and/or social needs. Respite care was hard to find even for short periods of time and worry about the future increased.

In addition, relatively high levels of skills deficit were reported with regard to sons and daughters with disabilities, e.g., adult sons or daughters were not able to dress themselves or look after their own personal hygiene. These and other basic life skills can be taught and learned through early behavioural intervention (Maurice, Green, & Luce, 1996). Given the political unrest and severe lack of service provision in Northern Ireland (Darby & Williamson, 1978) during their early childhood (average birth year 1976), these sons and daughters would not have benefited from recent advances in early behavioural interventions (Howard et al, 2005). As such, most of them displayed relatively high levels of helplessness (Seligman, 1972) and dependence on their parents/carers.

Early intensive behavioural intervention (EIBI; Howard et al, 2005) has been successfully used to extend the skills levels and behavioural flexibility of children with disabilities. Its uptake has been slow in Northern Ireland (Keenan, 2004). Children with disabilities who benefit from EIBI have more behavioural choices and consequently are able to lead more independent adult lives than the sons and daughters in this study (McEachin, Smith, & Lovaas, 1993).

- **Expanding behavioural choice**

Participants in this study showed that while some of the current care demands were met, generally there was a severe lack of suitable services. This is not only a challenge for carers, but also a question of the rights of the sons and

daughters with disability (Joint Committee on Human Rights, 2008). Given that the sample was comprised of sons and daughters who lived at home with their parents, one could ask to what extent the sons' or daughters' rights to make decisions as independent adults were considered. Most typically developing adults of their age would live independent lives away from the home in which they grew up. This was not an option for participating families because there was no suitable alternative accommodation where parents felt that their offspring would be cared for appropriately. Amongst other things, worry about inappropriate care or supervision or potential abuse was noted.

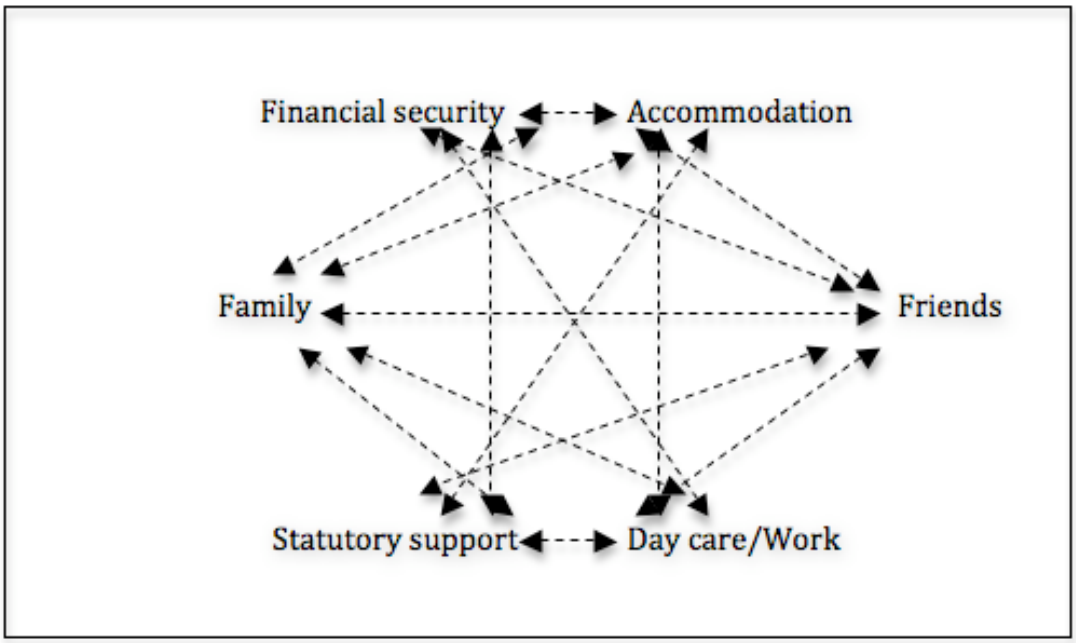
In situations of high demand and low supply, conflict and stress are inevitable (Hursh, 1984). With the lack of suitable sheltered accommodation, participants felt they had to compete for access. The lack of suitable accommodation and support services should not be news to service providers. Numerous reports have pinpointed this deficit (e.g., Bamford, 2006; McConkey, 2006). It seems that while society relies on older parents and informal carers to take full caring responsibility, and thereby making substantial savings, the situation is unlikely to change. Inadvertently, the huge amount of high quality care given freely and willingly by the parents reinforces, or increases the future probability of inactivity of service providers (see Figure 1).

Lipsitt (2005) draws attention to the perils of ignoring behavioural science; "sometimes our vision for the future requires not a leap in faith but a scientific jump-start" (p.203). The scientific jump-start is necessary to calculate future

care and accommodation needs on the basis of the number of children born with impairments and the number of people who suffer impairments later in life. In this way, reasonably accurate predictions can be made and provision planned well in advance. The reality evidenced in this report is that by-and-large these calculations are not followed by adequate action. Consequently older parents were expected to carry the full responsibility for care and futures planning against a backdrop of severe shortage of provision.

Necessary networks include extended family, friends, financial security, accommodation, statutory bodies, employment, and day care. Figure 5 illustrates the necessary network of social support.

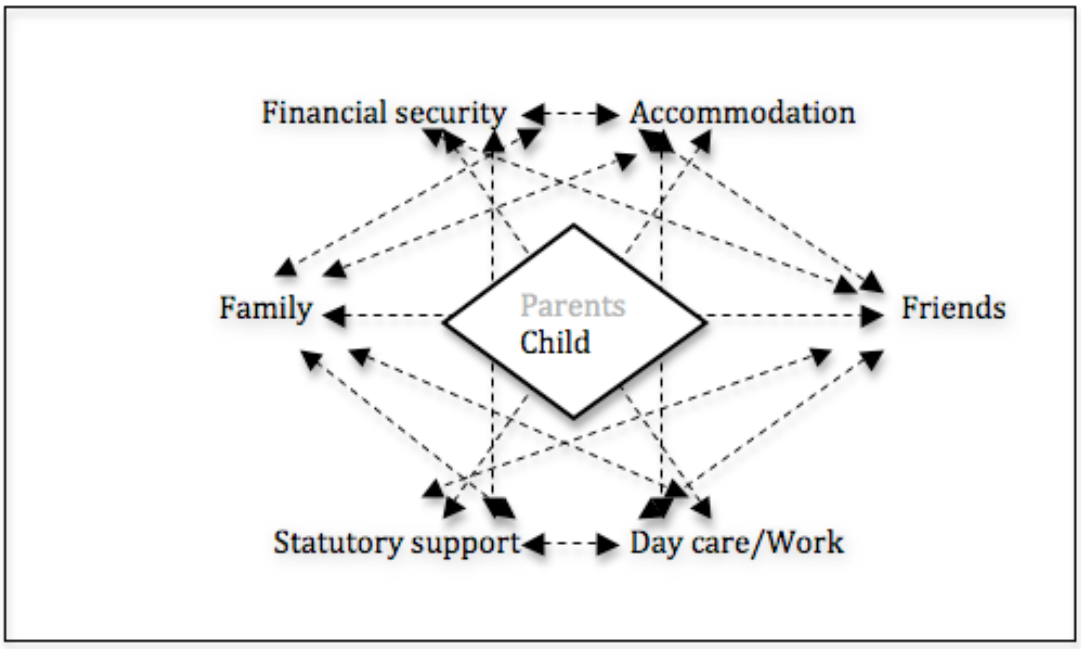
Figure 5: Illustration of necessary support network



These mutual interrelated relationships cannot be built overnight or in a crisis situation, they require planning and long-term partnership between all participants, including parents and sons and daughters with disabilities.

In cases where strong support networks were established during the lifetime of the parents, sons and daughters with disabilities will be *caught* securely in a safety net of support when parents are no longer available (Figure 6).

Figure 6: Illustration of parents/child at the centre of network of support



After taking on the Health, Social Services and Public Safety portfolio in May 2007, Michael McGimpsey said that, “one of the greatest challenges I faced was how to reform and modernise our health and social care system so that it is truly fit for the twenty-first century” (McGimpsey, 2008, p.2). This report shows the importance of including early intervention and early planning of service networks for older carers and their sons and daughters with disabilities.

Section 7: Conclusion and Recommendations

- **Summary**

A study of 29 parents/carers of 27 adults with disabilities was carried out. In-depth interviews showed a highly complex picture of interdependent relationships. On the one hand, ageing adults with disabilities clearly are vulnerable and require physical and social care as well as protection. Many of the problems identified in this research are a legacy stemming from a lack of investment in early behavioural intervention that leads to limited choices and restricted behavioural repertoires.

On the other hand, ageing parents and carers are vulnerable and require support; at times they too require physical and social care. Many of the problems described by ageing carers are due to the lack of science-based training for professionals, a deficit in available services, and a system too dependent on ageing carers carrying the full responsibility.

Participants felt responsible for their offspring in a way that differed from parents of typically developing adults. While obviously most parents feel a high level of responsibility for their children, even after their offspring have matured into adulthood, participants felt it differently. They did not want to *burden* their other children with caring responsibilities in the future; they did not want to expose their grandchildren to the experience of living with an uncle or aunt with disabilities. In a sense they felt responsible for their son/daughter with disabilities because they were the ones who gave birth to

them, and therefore they were the ones who had to care for them for life. These feelings are learned throughout a lifetime and cannot be divorced from the lack of support available. If children were viewed as a societal responsibility, regardless of levels of ability, these carers would not be under the same stress.

This report exposed a societal response to adults with disabilities that may be described with the precept 'Why should we care, they are not our children?' Findings reported here show that society will not be able to keep its *head in the sand* for much longer. Given that a large number of parents are at an advanced age, the societal *time bomb* of caring for older adults with disabilities is about to go off!

- **Recommendations**

1. Evidence-based early interventions need to be in place to enhance life skills and choices of individuals with disabilities.
2. An advocate should be available to each family throughout the life span, to help set up and coordinate appropriate networks of support well in advance.
3. Suitable alternative accommodation needs to be available for adults with all levels of additional individual needs.
4. Support services for adults with disabilities who live at home and their carers should be easily accessible, especially in rural areas.
5. Education and training for service providers needs to focus on evidence-based best practice to meet the needs of these families.

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Appendix 1

PARICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What the future holds: Caring for grown-up children with disabilities

People who are caring for grown-up children with disabilities often are under tremendous stress and worry about what the future holds. This research aims to find out what it is like to care for a grown-up child with disabilities and how parents make plans for the future. We hope to learn much from parents and be able to tell policy makers, professionals, and other parents about important issues faced by you.

You have been chosen to take part in the study because you are caring for a grown-up child with disabilities.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the service you receive.

If you decide to take part you will be interviewed by a member of the research team and asked to complete a brief questionnaire. The interview should not take longer than 45-60 minutes and researcher will be available to help with the questionnaire.

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that leaves the agency will have your name removed so that you cannot be recognised from it. Once the study is completed results will be presented in written papers and in oral presentations. Please let us know if you would like a copy of the results.

The Research Ethics Committee of the School of Sociology, Social Policy and Social Work of Queens University of Belfast reviewed the research.

If you have any further questions you can contact me, Dr Karola Dillenburger, at 02890975985 or email me at k.dillenburger@qub.ac.uk

Thank you very much for participating in this study
2007-10-04

(Form on headed paper)

CONSENT FORM

Title of Project: **What the future holds: Caring for grown-up children with disabilities**

Name of Researcher: Dr Karola Dillenburger

Please initial box

1. I confirm that I have read and understand the information sheet ☐ for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, ☐ without giving any reason, without services or legal rights being affected.

4. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Researcher	Date	Signature

1 for participant; 1 for researcher

Appendix 2

Semi-structured interview questions
What the future holds: Older Carers of adult 'children' with disabilities.

Interviewer instructions:
Before interview, print out for each interviewee: **Participant information sheet and consent form, GHQ-12, and interview schedule.** Ensure that your tape-recorder is working.

At beginning of interview: Get interviewee to read the participant information and sign the consent form (read it out if necessary). Only proceed if interviewee has signed the consent sheet. If not, discontinue and thank the participant for taking time to consider contributing to research.

During interview: If consent form signed, switch on tape recorder. Read out each question and give time to answer in full. Make sure that all questions are covered. Feel free to add any clarifying questions as necessary. Make notes during the interview on the interview sheet e.g. especially name and date etc. Start interview by saying:

"Thank you very much for agreeing to take part in this interview. The interview should take not longer than about an hour. I hope you don't mind if I tape-record this interview so that I can be sure not to miss out on anything you say."

1. Biographical details:
"Do you mind telling me your age?

Do you own your house? How many bedrooms do you have? Have there been adaptations to the house, for example to help with disability?

Is your husband/wife/partner living with you?

What do you consider your most positive things in life at the moment?

What do you consider your biggest challenges or problems at the moment?

How many children do you have? How many boys/girls? What ages are they?

What is the name and age of your child with disabilities?

What is the nature of those disabilities and when were they diagnosed?

Does [name of child] live at home all the time? If not, where does s/he live and in what type of accommodation?

Do other children or relatives live at home? If so, what are their names and ages?

How would you describe your relationship with your children in general (if there are more than one 'child').

2. What type of care do you provide? (e.g. personal care such as dressing, washing, toileting, feeding/ nursing care/ supervision/ administration of medicines / cooking and washing clothes/ organising activities, or any combination of these).

How much time does this take up throughout the week?

What do you consider the most positive thing in his/her care?

What do you consider the biggest challenge or problem his/her care?

3. Although you are the principal carer, do you receive any support in this from other family members (& if so, what is their relationship?)

Do friends or neighbours help out?

What aspects of care might they help with?

What do you consider the biggest help with him/her?

What do you consider the biggest challenges with him/her?

4. Do you receive any help with caring for [name of child] from Social Services (such as a care worker to help you look after [name of child] or with cooking and cleaning, a day care facility or a work placement for [name of child], respite if you request it)?

Do you have a 'care plan', and how was that decided? How often is it reviewed?

5. Has the help you receive (financial or otherwise) changed over the years in response to the changing needs of [name of child]?

If it has, were you able to discuss this with the providers? Did you have to actively ask for changes when you needed them or were they offered?

Has 'informal' support (family/neighbours/friends) changed over time? Were people more willing to help when [name of child] was small, or when he/she is older?

6. As you have grown older, and as [name of child] has too, how do you feel you both are coping with the level of care you are providing?

How would you describe your own health? good/fair/poor?

How would you describe your relationship with your partner?

How would you describe your relationship with [name of child with disabilities]?

7. If you were to become ill, even for a few days, who steps in to help with caring? Has this happened in the past?

How was this agreed? E.g. if you have arrangements with Social Services, did you have to ask for a meeting about what to do in such circumstances, or is it part of your care plan (if one exists)?

If family/friends help out, did you sit down and consult with them and draw up plans, or is it just understood that some of them will be there if needed?

8. If you were to become unable to provide the level of care you feel is necessary, have you made long term arrangements for [name of child]'s future needs?

What would they be?

Were you able to discuss these with – for example- Social Services? Have any agencies offered you any advice about the future, or have you had to seek it out for yourself?

Are you able to talk about this with [name of child]?

9. Have you set up any financial arrangements or arranged for other people to handle [name of child]'s legal affairs should you become unable to cope, or were no longer around?

When do you think is a good time to start planning such things?

10. What advice in general would you give to someone starting to plan their adult 'child's' future care?

Is there anything you wish you had known about earlier, or anything you might have done differently?

11. GHQ-12 to be completed. This can either be given to interviewee or read out by interviewer who circles the answers (if that feels more appropriate).

"*Thank you very much for participating in this interview. Your answers were very informative and helpful."*

Interviewer instructions: After interview: Please post back signed consent sheet and interview schedule with handwritten notes to Dr Karola Dillenburger, 53 Loguestown Road, Portrush BT56 8PD (02870823620). E-mail digitised interview recordings (as email attachment) to k.dillenburger@qub.ac.uk). Thank you!

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Help the Aged in Northern Ireland

Workers' Educational Association

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www.changingageing.org

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